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A phenomenological study of partners of people with Parkinson's disease who demonstrate communication changes

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**A Phenomenological Study of Partners of People
with Parkinson's disease Who Demonstrate
Communication Changes**

Elsie Janet Doherty

This thesis is submitted as part of the
requirement for the award of

Master of Nursing

at the
School of Nursing and Public Health
Edith Cowan University

Date of Submission September 2003

Abstract

Parkinson's disease is a common progressive neurological illness for which there is no known cure. While the cardinal signs are tremor, bradykinesia or slowness of movement, muscle rigidity and postural instability (Jahanshahi & Marsden, 1998, p.3) the patient may face an extended number of years experiencing all, or any combination of, the many other manifestations of the disease process. These manifestations include changes to various aspects of communication including loss of voice volume, diminished body language and loss of facial expression. All of these affect both verbal and non verbal communication.

Given the progressive nature of Parkinson's disease the patient may often require both physical and emotional support for many years. The long term partner or spouse often provides this care and support. There is a paucity of literature discussing the impact of communication changes or difficulties on the partner or spouse. Thus a study into the life experience of the partners of people with Parkinson's disease who demonstrate communication problems is needed. The aim of this study was to explore the experiences of partners of people with this neurological diagnosis and whose communication is affected.

A phenomenological approach was utilised to explore the impact of communication changes on the partner of a person with Parkinson's disease. Five participants took part in this study. Four of the participants responded to an advertisement placed in the Western Australian Parkinson's Association newsletter. The remaining participant volunteered to be part of the study while she and her husband were on holiday in Perth, Western Australia from overseas. All of the participants were female and their husbands had been diagnosed with Parkinson's disease for extended periods of time, ranging from five to fifteen years. In depth interviews were audio taped and transcribed verbatim. The data from these interviews were analysed using the method described by Colaizzi (1978). Data were described and interpreted and common themes were extrapolated and analysed. The three major themes emerging from the interviews were: The Partner/Carer Interface, Emotional Turmoil and Ways of Coping. The Partner/Carer Interface is made up of three sub themes, "life before diagnosis", "the point of diagnosis" and "sharing the disease." The second theme, Emotional Turmoil, includes the sub themes "confronting the physical, "the

condition always wins” and “social isolation”. The third theme addressed the skills necessary to cope with the future, or Ways of Coping. This theme encapsulates minor themes of “knowing the beast”, “sharing the burden” and finally preparing for “the road ahead”.

Based upon study findings recommendations are made in relation to care provision, patient education and community support. The need for further research has been identified, specifically into the diverse gender issues related to communication and the role of care giver. In addition the need for health professionals with an extensive knowledge base of this neurological condition has been identified as essential for quality nursing management.

Declaration

"I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text."

Signature:

Date: 16th December 2003.

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Glossary

The terminology listed below is often used in describing and discussing Parkinson's disease. Throughout the thesis the terminology is noted in bold print.

Aphasia	Inability to speak
Basal ganglia	A set of structures scattered deep within the brain
Bradykinesia	Slowness of movement
Dopamine	A neurotransmitter necessary for normal movement (deficient in Parkinson's disease)
Dyskinesias	Involuntary uncontrollable movements
Dysphagia	Swallowing difficulties
End of Dose Failure	Wearing of medication before next dose is due
Hypokinetic dysarthria	Change in speech pattern with the voice becoming progressively quieter, weaker and less distinct to the point of being unintelligible
Light writer	An electronic communication aid which can be programmed to "speak"
Kinesia paradoxia	The ability to move following a stimulus even when the patient is normally unable to initiate movement
Micrographia	Change in handwriting, becoming progressively smaller as the person writes
Microphonia	Change in speech pattern related to loss of volume
Neuro-Psychiatric changes	Development of hallucinations, paranoia and psychosis
Pallidotomy	The placing of a lesion in the globus pallidus, the output gateway of the basal ganglia
Seborrhoea	Increased discharge of oily secretion from sebaceous glands of the skin
Striatum	A structure within the basal ganglia comprised of the caudate nucleus and putamen
Substantia Nigra	A small area of the brain that produces the chemical Dopamine. This area degenerates in Parkinson's disease leaving the brain with inadequate amounts of the chemical

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CHAPTER ONE

Introduction

The ability to communicate effectively is regarded as essential for a healthy social relationship and it is commonly accepted that any impairment to the communication process will have a negative impact on the quality of such a relationship. It can therefore be assumed that a disease process which affects communication will in turn affect the interpersonal communication between long term partners. This phenomenological study investigated the experience of partners of people with Parkinson's disease who demonstrate communication changes.

Background and significance of the study

In 1817, the English physician James Parkinson described the neurological condition which was later to bear his name. He had no understanding of the causation of the disease and few suggestions for treatment but his detailed and sensitive observations have ensured his place in medical history. In recent years with advances in scientific development the enigma that is Parkinson's disease has been the subject of much discussion and research, aimed at achieving an improved understanding of the condition. Because of the diverse effects of Parkinson's disease the impact of the condition reaches far beyond the patient to influence those living and dealing with the person affected by the condition.

Parkinson's disease is a common progressive neurological condition for which there is no known cure. It is agreed that the condition affects 1:1000 of the population over the age of 65 and 1:100 over 75 (Morris & Iansek, 1997, p.2). The tetrad of diagnostic signs is tremor, slowness of movement, muscle rigidity and postural instability (Waters, 1999, p.11). In addition to these signs and symptoms upon which diagnosis is based, the disease can affect every aspect of communication. It is estimated by health professionals that between 50% and 75% of people with Parkinson's disease develop communication changes (Countryman, 1998, p. 10; Scott, 1998, p.4).

Muscle rigidity and **bradykinesia** can in part lead to a monotonous tone and reduced volume of speech thereby depriving people with the disease of 93% of their communication skills (Scott, 1998, p. 4). Rigidity of facial muscles can lead to a mask-like expression and this feature combined with reduced body language may be misinterpreted as lack of interest or lack of understanding (Oxtoby, Williams & Iansek, 2002, p. 92-93). The disease has the potential to affect written communication by affecting the size and clarity of handwriting. These changes, in addition to subtle personality manifestations result in potential problems in communication which will affect both the person with the condition and those closest to them. There is much literature available outlining the impact of Parkinson's disease on communication for the affected person (Countryman, 1998; Parkinson's Disease Society, 2000; Schulz & Grant, 2000; Scott, 1998). The various forms of speech therapy and strategies aimed at maintaining or improving communication are well documented (Baker, Ramig, Johnson, & Freed, 1997; Ramig, Sapir, Fox, & Countryman, 2001). These include the Lee Silverman Voice therapy which is primarily aimed at raising the volume of speech and clarity of articulation. However the impact of the communication changes on the partners has not been explored.

It is rare that a person with the disease who experiences communication changes will verbalise their limitations and the impact and potential impact of those limitations on those closest to them. However one Australian author with Parkinson's disease who continues to conceptualise his sentiments through poetry has insight into the future when normal communication with his wife may be impossible. Greene (2000, p. 31) who was diagnosed at an early age wrote the following poem to his wife when he realised that his communication was becoming affected. His poem is entitled "Do not think badly of me."

Do not think badly of me when I have to go
 past where you have to stop
 or if at times I seem to be in
 some far distant country of my own;
 do not believe that I don't want to be
 where you are, for it is not so,
 nor could it be when every joy I have known,
 I've known through you.
 No I would never go, given the choice.

I seldom tell you, but you surely know
 just how aware I am that every day
 you have a choice – and chose to walk
 with me along these roads I walk against
 my will; willingly going where I am slow
 to go, sharing a future we can only know
 from ambiguous answers to half asked
 questions. I wonder if you really know
 what strength your presence gives me.

And if in the far future there's a road
 that I must walk alone in deepest silence;
 then I will walk that road and know
 your love walks with me. Do not think
 badly of me if I have to go past where
 my words all stop; our love transcends
 the things we think we know, and while
 I breathe, I will be whispering low; and
 just below each breathe, the words...
 "I love you".

This poignant piece of work clearly describes the awareness of the author to the potential loss of his communication abilities and the impact on his loved one. However, we can only surmise the feelings of his wife as she walks this path with him.

In a multi-centred European study people with the condition ($n = 6615$) reported that communication changes were common to 68% of those surveyed (European Parkinson's Disease Association, 1999). These changes can take many forms affecting both verbal and non verbal means of communication. The study in Europe while surveying the symptoms of the people with the condition did not however address the experiences of those closest to the people with Parkinson's disease. My study addressed that lack of insight into the lived experience of the partners of people with Parkinson's disease who demonstrate communication changes.

My interest in Parkinson's disease originated in the first few months of my nursing career. In 1967 in Belfast, Northern Ireland I was a student nurse working on a medical ward caring for patients with Parkinson's disease. During my time on that ward the drug levodopa was being trialled as an innovative treatment for the condition and the transformation of patients from a stiff, rigid tremulous state of immobility to a state of near normality made a great impression on both me and my future practice.

At that time the medical and nursing worlds were unaware of the long term outcomes of levodopa therapy and its introduction was hailed as a miracle. However within a few years it became obvious that the 'miracle' treatment brought with it some side effects which were to prove as challenging as the disease process itself. The development of **dyskinesias, end of dose failure and neuro-psychiatric changes** resulted in unforeseen challenging aspects of the management and subsequently a more conservative use of medication. Therefore it became obvious that both the disease and drug related problems experienced by these patients and their families would continue to puzzle and challenge health professionals. The implications for the people with the disease and their partners would remain immense.

The prevalence of Parkinson's disease is estimated as approximately 160 cases per 100,000 population and increases with age (Waters, 1999, p. 17). The worldwide commonality ensures that the majority of nurses will care for patients with the condition at some time in their nursing career. This has been true in my nursing career and thus the personal interest in this disease remained a feature of my transition from novice to expert nurse. In both Northern Ireland and Australia, patients with Parkinson's disease have presented me with personal and professional challenges.

The genesis of this study on the impact of communication changes on the partner of people with Parkinson's disease arose during my employment as a Day Hospital Coordinator in Perth, Western Australia. An elderly male patient with Parkinson's disease had been attending the day hospital for physiotherapy aimed at improving his mobility. Because of uncertainty as to whether he could continue to live at home with his wife as the main caregiver a team meeting was arranged. During this meeting the wife of the patient quietly stated.

We have been married for over sixty years. I don't care if he can't walk or go to the bathroom. All I want is that we can communicate for the last few years. I would love to hear him again (Mrs. A, personal communication, September 27, 1991).

The impact of that statement has remained with me to the present time and influenced my career path and ultimately my desire to learn more through the research process.

In my current position as a Parkinson's Nurse Specialist since 1998, I have observed the impact of Parkinson's disease on relationships between couples. The changes observed have been more than the gradual introduction of the physical acts commonly associated with care giving. Frequently one observes the dynamics of the relationship changing even

when the physical role of caregiver is not clearly demonstrated. In most cases, these changes are the subject of observation only because while some partners of people with Parkinson's disease openly discuss their situation and relationship issues the majority do not volunteer their feelings and thoughts on the subtle personal experiences of living with the disease. These thoughts often remain unspoken and therefore are often unacknowledged.

The use of observation or 'clinical gaze' in the medical perspective has been described as an observing gaze which tries to transform that which is seen into language that can then be used to teach others (Madjar & Walton, 1999, p. 100). This is the basis for the use of phenomenology as a research method. In a phenomenological study the researcher focuses on what is ordinary for a group of individuals and the outcome of the study will be an understanding that is extraordinary (Munhall, 1994, p. 4). It is by the utilization of the clinical 'listening gaze' of phenomenology that we can confirm or repudiate clinical experience. In living with their partners who have Parkinson's disease and demonstrated communication changes the participants in this study are experiencing a life which is normal to them and by its normality it has become ordinary. It is by exploring their experience that the ordinary will become extraordinary. In this study the 'listening gaze' was focused on a group of partners of people with Parkinson's disease who demonstrate communication difficulties or changes.

Purpose of the Study

The purpose of the study is to describe and interpret the lived experience of partners of a number of people with Parkinson's disease who demonstrate communication changes. Through the analysis of data obtained during interviews the meaning of the phenomenon will be explicated and illustrated. This information will contribute to the body of knowledge related to Parkinson's disease and communication between long term partners and support recommendations for future practice.

The Study Objectives

The study has sought to address the lived experience of the partners of a number of people with Parkinson's disease who demonstrate communication changes. The objectives of the study are to:

1. Describe the lived experience of the partners of a number of people with Parkinson's disease who demonstrate communication changes;
2. Describe common elements, themes or patterns of experiences related to Parkinson's disease and communication changes;
3. Interpret and analyse the meaning of these experiences; and
4. Contribute to the body of knowledge specific to Parkinson's disease.

Structure of the thesis

This chapter has outlined the background to the study on the lived experience of partners of people with Parkinson's disease who demonstrate communication changes. The purpose is to develop an understanding of their experiences and extrapolate common themes and sub themes which will be discussed in detail. The research objectives are outlined. As terminology specific to Parkinson's disease is used throughout the thesis I have provided a glossary which is to be found immediately following the contents page. In the body of the thesis this terminology is written in bold type.

Chapter Two presents a review of the literature pertinent to Parkinson's disease and communication. This encompasses both classical and recent literature on Parkinson's disease and communication in addition to the role of the nurse in caring for the patient with Parkinson's disease and their family.

Chapter Three examines the methodology chosen and the rationale for this choice. The study design, sample and procedure for data collection and analysis are examined. The validity, limitations and ethical considerations related to the study are discussed. Chapter Three includes with a table outlining the themes and sub themes resulting from the analysis of the data.

Chapters Four, Five and Six each outline one of the three major themes extrapolated from the interview data. Each major theme has three related sub themes which are discussed in relation to the literature and supported by direct quotations from the participants.

Throughout the thesis direct quotations are in italics and each participant has been allocated a pseudonym.

Chapter Seven concludes the discussion of the phenomena revealed by the study. The recommendations resulting from the findings are discussed in relation to clinical practice and implications for further research. The implications for education of people affected by Parkinson's disease and health professionals are addressed. In addition, the ongoing development of the role of Parkinson's Nurse Specialist is discussed.

CHAPTER TWO

Literature Review

Introduction

Parkinson's disease is a common, progressive neurological condition for which there is no known cure. The signs on which diagnosis is based are tremor, **bradykinesia**, muscle rigidity and postural instability (Jahanshahi & Marsden, 1983, p.3). In addition to these cardinal signs the impact of Parkinson's disease is immense and the manifestations varied. Parkinson's disease is more complex than the medical definition suggests. As is true with many other diseases, Parkinson's disease has a social dimension affecting all aspects of daily life and is unpredictable in the long term. The impact of Parkinson's disease on communication is profound and potentially all aspects of communication can be affected. These include both verbal and non verbal communication skills.

The purpose of this literature review is to position this study and the findings extrapolated from the data within the context of literature. This chapter will review and discuss the literature pertaining to Parkinson's disease and in particular the relationship between the disease process and communication. The impact of the communication changes on long term partners of the person with the disease will be discussed as related to the literature.

Parkinson's disease

Parkinson's disease is related to the loss of dopamine producing pigmented nerve cells in the **substantia nigra** in the **basal ganglia** within the midbrain. The loss of these nerve cells results in a depletion of **dopamine**, a neurotransmitter, in the **striatum** (Lieberman, 2002, p.16-18). Parkinson's disease is a world wide phenomenon, the prevalence of which increases with advancing years. It is agreed that Parkinson's disease affects 1 in 1000 of the population over 65 years of age and 1 in 100 for people over 75 years of age (Morris & Iansek, 1997, p.2). It is currently estimated that the figures for Australia are approximately 78, 000 (Fung, Morris & Pell, 2002, p.7). It can be postulated that the incidence of Parkinson's disease will increase in

the future as the ageing population increases. The Australian Bureau of Statistics (2003, p.3) population projections demonstrate that population aging will continue. These figures predict that Australia wide, the proportion of the population over 65 years is expected to increase from 12% in 1999 to between 24% and 27% in 2051. The proportion aged 85 and over is expected to almost quadruple to almost 6% in 2101. If these projections are accurate it is inevitable that the incidence and prevalence of Parkinson's disease will rise accordingly.

Parkinson's disease is not solely confined to the elderly population, 15% of people with Parkinson's are younger than 50 (Lieberman, 2002, p. 2). Young and juvenile onset Parkinson's disease sufferers are subsets of the idiopathic Parkinson's disease group. The literature varies a little in defining the criteria for these groups but it is generally accepted that Young Onset is seen in people 40-50 years of age, while Juvenile Onset is seen in people less than 21 (Doherty & Lyle, 2003, p. 14). Thus any study which examines the far reaching impact of Parkinson's disease on the whole population will be worthwhile.

The earliest written report on Parkinson's disease is attributed to Dr. James Parkinson in 1817 in his *Essay on the Shaking Palsy* (Parkinson, 1817). This classic description remains an accurate account of the characteristics of Parkinson's disease. Dr. Parkinson gave a detailed description of the communication difficulties associated with Parkinson's disease with statements such as "... words scarcely intelligible" (p.3) and "... the tongue now outruns the mind" (p.9). Thus we can see from the genesis of literature on Parkinson's disease that the changes in communication have always been a factor of note.

It is interesting that Dr. James Parkinson did not document the lack of facial expression as typical of the condition which in later years was allotted his name. This omission is of special note given that his description of Parkinson's disease was a result of an observational study conducted in the streets of London in 1817. To discuss the reason for his not describing the facial masking would be purely conjecture and is not relevant to the purpose of this research.

Pallis (1971) in his article on clinical problems described in detail the epidemiology, natural history and signs and symptoms of Parkinson's disease, but failed to describe any aspect of communication changes. It can be seen that the impact of communication changes and the impairment of speech, facial expression and writing were not given a high profile in early

researchers in Parkinson's disease literature.

Medical literature explores Parkinson's disease, its manifestation, possible causation and optimum modes of treatment (Calne, Duvasin & Koller, 1994; Marsden & Olanow, 1998; Quinn, 1990). However, these prominent authors fail to address the speech difficulties associated with Parkinson's disease. The omission of communication difficulties from these articles is not due to the authors' avoidance of the non- motor manifestations of the disease. Considerable emphasis is given to **dysphagia** and **seborrhoea**, while **microphonia** and loss of facial expression are ignored. This omission highlights the gap in research related to the impact of the disease process on communication. Jahanshadl and Marsden, (1998, p.14) describe speech difficulties and masked expression under "minor symptoms." These symptoms may have minor significance in terms of prognosis and life expectancy but they are not minor in terms of communication ability and quality of life.

The omission of descriptions of communication changes could appear to confirm the lack of value given to these most basic components of communication. Although they are not the cardinal signs and symptoms on which medical diagnosis is based, they are the symptoms which have far-reaching consequences for interpersonal relationships. The paucity on information regarding the communication changes and their subsequent impact on relationships demands further study.

Communication

Communication involves the sending of information and messages between a sender and a receiver through several means of transmission including speech, writing, facial expression or body movements. The communication process is also influenced by factors such as the type of relationship that exists between those involved in the process, the status of the participants and the content of the message (Fuller & Schaller –Ayers, 1990, p.387). The authors cite in particular the emotional, physical and cognitive status of the sender or receiver as being major factors influencing the process.

The gift of communication is much more than the interchange of information between people. It can include the process of exchanging feelings, desires and needs in addition to

information and opinions. Communication is an essential part of human nature, and is used in a variety of ways to maintain social ties and to facilitate the transmission of feelings between living beings (Countryman, 1998, p. 9). Communication and all that it involves is therefore an essential component of human nature. If a relationship is to endure the pressures of modern life it is essential that each partner is able to communicate their hopes, dreams and feelings.

Communication is generally categorised into two types, verbal and non-verbal. Verbal communication uses spoken or written word, and non-verbal communication encompasses other aspects such as gesture, posture and facial expressions. Schuster (2000, p. 14) cites research by Mehrabian (1972) as agreeing with most observers of communication that, although both aspects occur concurrently, the majority of communication is non-verbal. The breakdown given by Mehrabian (1972) is appearance and body language accounting for 55 % of the interpretation of the message, tone of voice accounts for 38 % and the spoken word accounting for the remaining 7%. Parkinson's disease is a common neurological condition that impacts on each of these components of communication.

Communication is a dynamic process, and if anything interferes or impedes the flow then the relating process will break down. The result of this breakdown can include misunderstanding, confusion and in the long term, frustration for both parties. These aspects of communication breakdown are true in all aspects of day to day life, but are especially pertinent when the ability to communicate is impacted by a neurological disease process.

Communication and Parkinson's disease

Countryman (1998) in writing for the National Parkinson Foundation estimates that 75% of individuals with Parkinson's disease experience changes in voice and speech. These changes can range from mild to severe. Facial expression and tone of voice are especially important in conveying feelings. The masked expression, stooped posture and lack of gestures are deemed to be barriers to communication (Scott, 1997, p.11). When these signs are combined with poor articulation and decreased volume as in Parkinson's disease it is clear that difficulties in communication will arise. Characteristics of **hypokinetic dysarthria** in Parkinson's disease include monotonous and reduced pitch and loudness, a variable rate and imprecise consonants (Schulz & Grant, 2000, p.60). When these occur in combination with loss of facial expression

due to muscle rigidity and paucity of gesture (Scott, 1998, p.3) the result can be both distressing and confusing for both patient and family members. This “masking” can suggest not only a lack of understanding or involvement but also a lack of interest. This perceived presentation will impede communication at all levels but in particular communication between long term partners.

The effects of reduced expression were studied using innovative methodology in Britain in the 1980's. In this seminal study Pentland, Pitcairn and Grey (1987, p.307) utilised silent video recordings of four people with Parkinson's disease and four people with Ischaemic Heart Disease. The potential for ageism was overcome, possibly by chance, in that the people with Parkinson's were of a younger average age group (range 37-59 years) than those with heart disease (43-71 years). The videos were shown to 91 health professionals who were asked to record 15 aspects of the participant's mood, intellect and personality using a visual analogue scale. The results indicated that the people with Parkinson's disease appeared more anxious, hostile, suspicious and unhappy than the cardiac cases. The outcome of this study is significant in that the people with Parkinson's were not in an advanced stage of the disease process and therefore were not affected by the social isolation usually associated in more severe cases.

It is of interest that Pentland et al., (1987) did not seek the opinions of the partners in their study. They would be the main co-recipients of all interactions with the person with Parkinson's and their experiences would have provided some insight into the effects of long term communication with people with Parkinson's disease. Poor communication between couples is commonly reported as one of the main issues in marital breakdown. When communication difficulties such as loss of expression, reduced volume and a chronic disease process are all present one would expect that this would be acknowledged in a study of this importance. If health professionals are unaware of the risk of misreading the masked faces or paucity of gesture then one must address the possibility that the partner may misinterpret the cues given. It is a challenge to all health professionals to ensure that the partners of all people with Parkinson's are made aware early in the disease process that this risk exists.

The family of Mrs. Lee Silvermann, an American with Parkinson's disease expressed the desire of all families affected by this condition when they stated, “ if only we could hear and

understand her speech”(Ramig, 1998, preface). Mrs. Silvermann became the eponymist for the innovative speech therapy based on raising the volume of people with Parkinson's disease who experience microphonia and unclear speech. This speech therapy is now utilised world wide in centres for treatment of Parkinson's disease. It becomes clear, in clinical practice, that the heart felt desire to communicate clearly and effectively is a common theme identified by partners and families who are living with the communication changes imposed by Parkinson's disease.

Morris, Iansek and Kirkwood (1995), Australian clinicians, produced a book which is a resource for clients with the disease. They focus on both motor and non motor issues as a consequence of the basal ganglia disturbance resulting in Parkinson's disease. Although the chapter on communication difficulties gives practical hints for the person with the condition it fails to address the needs or feelings of the person with whom the person with Parkinson's will be communicating.

The literature acknowledges the commonality of speech disorders in Parkinson's disease and the potential for disability due to communication changes and states that in spite of this, speech therapy is the least utilised non-pharmacological therapy in Parkinson's disease (Weiner & Singer, 1989, p. 361). A British study in 1988 found that as few as 3% of sufferers of Parkinson's disease had contact with a speech pathologist (Baker, 1988, p. 17). Studies exist which discuss the efficacy or otherwise of speech therapy in Parkinson's disease (Pearson, 1995; Sarno, 1968; Schulz & Grant, 2000). Much that is written suggests that in the long-term, speech therapy has little value. Weiner and Singer (1989 p.361) report that objective evaluation of speech therapy is difficult due in part to the fluctuating effects of medication. In addition they report that there is a commonly held belief that speech therapy is only demonstrated to be of value while it is ongoing. These comments have been attributed to the families of people with Parkinson's and although this outcome is disappointing it is encouraging to see that the opinions of the partners have been sought. The next logical step would be to explore the impact of living with someone whose ability to communicate on all levels has been compromised by a neurological condition such as Parkinson's disease.

Ramig, Bonitati, Lemke and Horii (1994) agree with the high incidence of speech involvement in Parkinson's disease and the partial failure of medication to relieve these symptoms (p.79).

The Lee Silvermann Voice Treatment was devised by these authors as a specific treatment for **hypokinetic dysarthria**. This intensive therapy has been evaluated by the clinicians who were initially responsible for its delivery. The evaluation involved forty clients whose most commonly presented symptom was reduced volume. The monotone associated with the disease is clearly documented and addressed, however in the treatment under evaluation no strategies addressing paucity of gesture or facial expression are utilised. As the communication process involves more than volume of speech the inclusion of non verbal communication may have added another dimension to the outcome of a treatment for communication changes. The inclusion of the spouses in concurrent educational sessions may have addressed this issue and it is reassuring that the partners' perceptions of the subjects speech were collected pre and post treatment. The paper goes on to state that only fourteen spouses of the forty subjects assessed completed the visual analogue scale for the effectiveness of the treatment. Thus we can see that the methodology used for study by Ramig et al. (1994) does not reflect the sensitive nature of communication within a relationship, although it served the purpose of evaluating this accepted and renowned method of treatment. This would suggest that an area as complex and personal as communication between long term partners would be enriched by a qualitative study carried out by a health professional who views the partners in a holistic approach. The data generated from the study by Ramig et al. (1994) was considered to have no statistical significance.

Parkinson's disease associations world-wide are prolific in the production of self-help and educational literature for people with the condition and their families. One example is *Speaking Out* (Countryman, 1998). This publication specifically addresses communication issues and combines the clinical and emotional impact of communication problems and the partner is at all times acknowledged as having a role to play in ongoing therapy. The assistive strategies for partners outlined in this publication are aimed at their role in improving the communication skills of the person with the condition.

It is clear that there is a gap in the area of assisting partners and family members to cope with the changes in communication which commonly result from Parkinson's disease. The majority of people with Parkinson's disease continue to live in the community and are endeavouring to utilise their remaining communication skills in every day interaction with partners, family members and the general public. The issue of a grandfather's communication with his

grandchildren is of more long term importance than how he is perceived by a health professional. The non verbal spontaneity of an affectionate glance or wink of an eye between long-term partners can be greatly impaired by this common neurological condition. I feel that more understanding and weight should be given to this area of the disease process and the resulting effect on those “silent” partners who are carrying the burden of care giving.

The impact on a relationship with a long term partner is at greater risk of frustration for both parties because of communication changes. This is highlighted by Sandi Gordon, an American author, diagnosed with Parkinson's disease at the age of 30 who writes in a Parkinson's association newsletter: “ The tremendous strain of Parkinson's disease in a marriage is rarely addressed” (2000, p. 6). This emphasises that this is an aspect of Parkinson's disease which may be easily overlooked by health professionals.

The effect of Parkinson's disease on communication between partners

In recent years there has been a shift away from long term care in hospitals or permanent care facilities to community based care within the home environment and this trend has the potential to impact on the number of partners providing on going informal care within the home. A British handout on Parkinson's disease and the role of the nurse (Baker, 1997) states that while the number of Parkinson's disease patients will increase the number of relatives, or partners, giving care will diminish. This report states that:

In 1920 a couple in their 80 ' s would have had 42 relatives able to care for them, 14 of whom did not have jobs outside the home. To- day people over 75 have on average 11 female relatives, with only 3 having no job outside of the home. From these figures we can deduce that the burden of care, and all that that involves, will fall more and more on fewer people and isolation will increase (p.2).

These figures are supported by a General Household Survey in the United Kingdom which revealed that there are as many as six million informal caregivers. Fifty percent of these are providing care for more than 80 hours per week (Koffman & Taylor, 1998 p. 16). The numbers of informal caregivers, specifically partners or spouses, in Australia would be proportionate to the population. The impact of communication difficulties may not be classified as criterion for the role of care giving and therefore this group of partners may not be included in these figures.

While we are aware that Parkinson's disease is a common neurological condition there are few studies available which address the impact of difficulties in daily living on either the person with the condition or their partner. A needs assessment for planning purposes (Parkinson's Disease Society, 1994) utilised a survey of patients with Parkinson's disease in Aberdeen, Scotland. The data available from the Scottish study provides a breakdown of the disabilities experienced by those with the condition. The results show that 65% of the screened population (n= 267) demonstrated speech difficulties and a further 65 % had writing difficulties (Mutch, Dingwall-Fordyce, Downie, Paterson & Roy, 1986). These results, when seen in relativity to other manifestations of the disease, have even more impact. In the Aberdeen study the reported presence of a shuffling gait is 67% and tremor in the right arm, 55%. Thus this survey indicates that speech and communication is reported as a major issue in Parkinson's disease by those affected by the condition.

Mutch et al. (1986) attempted to address the potential needs of people with Parkinson's disease and as the authors point out, when there is a lack of a specialist key worker in the field the screening for those needs is often a haphazard process. At the time of the needs assessment the role of nurse specialist had yet to be introduced in the United Kingdom. The introduction of the role of the Parkinson Nurse Specialist, initially in the United Kingdom and in recent years in Australia has ameliorated the process of evaluating and co-ordinating optimum care of people with Parkinson's disease.

An Australian study by Katsikitis, Davis and Burrow (1996) involving a survey of people with Parkinson's disease was carried out with the purpose of assessing and documenting the level of disabilities affecting people with the condition. The volunteers, randomly selected, were recruited from the South Australian Parkinson's Association. The mean age of the 200 participants was 61 years and the mean duration of the disease process was 10.9 years. This study includes the assessment of both speech and facial expression. This survey found that 23% of the sample demonstrated speech difficulties and 39% were aware of facial expression involvement. The data obtained from the partners of the Parkinsonian was in agreement with these figures. It adds value to these figures when we note that 71% of the participants were in a marriage or de-facto relationship. An acknowledged limitation of this study was that it was carried out by non-clinicians. It is timely with the recent introduction to Australia of the role of Parkinson's nurse specialists that a further study into the impact of communication

impairments on the partners of the people with Parkinson's disease is carried out.

Grossmith (1997) in discussing the effectiveness of a day hospital rehabilitation programme for patients with Parkinson's disease includes speech as a variable however the experiences of those communicating with the person with Parkinson's disease were not reported. This omission highlights the lack of understanding the changes in communication and the impact of those changes have on a relationship where one partner is affected by a neurological condition. The objective in nursing is to provide support to such a client and the partner.

The support and caring that is necessary to address the emotional needs of patients and partners who are affected by a neurological condition such as Parkinson's disease cannot be delivered through technology or medication. Geary and Hawkins (1991) explored the role of caring which can lead to healing when no cure is possible (p.9). These authors quote Cassell (1976) in classifying illness as that which is experienced by the patient whereas disease is what is happening within the body or organ (p. 5). Thus it is the illness that must be assessed in the care of people with Parkinson's disease and the affect of that illness on the partners. Carrying this distinction further leads to the development of their hypothesis that the nurse can act as a healer. The suitability of the nurse as a healer is attributed to the holistic approach used in nursing, the continual contact by nurses with patients and the healing behaviours already implemented by nurses (Geary & Hawkins, 1991, p. 11). The availability of a community based nurse with specialist knowledge of an illness and subsequent awareness of the personal experience of those affected by that illness could address the role of the nurse as a healer.

Parkinson's Nurse Specialist

The advent of the role of Parkinson's Nurse Specialist, initially in the United Kingdom (1988) and a decade later in Western Australia, has transformed the care and approach to caring for people with Parkinson's disease. This role enables the nurse to develop specialist knowledge of the condition. It is this expert knowledge that enables him or her to become intimate with all aspects of the condition. This expertise is not limited to caring only for the person with the condition, but extends to caring for the partner and family members. The introduction of Parkinson Nurse Specialists has moved the focus of the care of people with this condition from the previously used medical model to a shared care community based approach. This approach acknowledges that this condition has a multi-factorial impact on both those

diagnosed with the condition and partners and family members.

The role of the nurse specialist is to educate, support, monitor and advocate for clients. The majority of literature available on the role of the Parkinson's Nurse Specialist originates in the United Kingdom where the role was first introduced in Cornwall in 1989 (Livesly, 1992; Maguire 1997; Noble, 1998). Maguire, a British Parkinson's Nurse Specialist, (1997, p.35) encourages nurses working with patients with Parkinson's disease to act promptly following diagnosis in offering both patient and partner information regarding communication difficulties, thereby addressing the problem before it becomes a major issue.

Livesey (1992, p.30) a British Parkinson's Nurse Specialist addressed the issue of non-verbal communication deficits in her paper on Parkinson's disease. She explored the impact of many aspects of the condition on the individual affected by the condition and takes a holistic approach to each symptom. In addition to communication changes, both verbal and non verbal, the potential lack of stimulation and social isolation are addressed as features requiring assessment and intervention. Livesey goes on to support the findings of Pentland et al. (1987) when she states that this lack of expression may be interpreted as a deficit in cognition rather than a result of facial muscle rigidity. However, the affect of these symptoms on the partners or family members is not discussed by Livesey (1992).

The impact of community based specialist nurses for Parkinson's disease has been evaluated in the United Kingdom (Jarman, 1998; Jarman, Hurwitz, Cook, Bajekal & Lee, 2002; Reynolds, Wilson- Barnett, Richardson, 2000). These studies addressed both the quality of life and satisfaction of patients receiving care from nurse specialists in addition to a comparison in cost and reduction in hospital admissions. A recent study by Jarman et al. (2002) was a two year randomised controlled study of 1859 patients with Parkinson's disease in the United Kingdom. In addition to patients completing a validated questionnaire twice during the evaluation period, face to face interviews by trained independent interviewers were conducted. The outcome was that there was a significant improvement in subjective well being of patients cared for by a nurse specialist. This improvement was achieved without an increase in health care costs. The authors go on to comment that a reported improvement in subjective well-being is significant when one is assessing a relentless progressive condition (p. 1075). These findings are echoed by Horrocks, Anderson, and Salisbury (2002) who carried out a meta-analysis of randomised

controlled trials and observational studies comparing British nurse practitioners and doctors providing care at first point for patients with a variety of conditions. The results indicated that the nurse practitioners provided longer consultations and that patients reported a high degree of satisfaction with no difference in health outcomes when dealing with nurse practitioners (p. 820). However, the most recent evaluation of the Parkinson's nurse specialist role was carried out in North Wales and the outcome of this survey was that a Parkinson's nurse specialist with a potential client base of 300-400 patients saved the local health authority approximately £ 50, 000 per annum (B.J. Graham, personal communication, July 18, 2003).

The introduction, development and evaluation of the role of a nurse specialist are natural forerunners to the development of a nurse practitioner in this area. It is therefore imperative that nursing research be carried out by clinicians in the field who are delivering expert care and are in tune with the needs of both their patients and the partners. This study into the lived experience of the partners of people with Parkinson's disease who demonstrate communication changes is such a study that will add to the body of knowledge in this field. If this can be achieved for Parkinson's disease then the results may be transferable to any disease process, which impacts on communication such as Cerebral Vascular Accident and Motor Neuron Disease.

Summary

The literature has revealed that there are both nationally and internationally an availability of studies of diverse methodologies which address communication changes in patients with Parkinson's disease. In the United States the focus has been on the efficacy of speech therapy while in the United Kingdom the availability of resources for people with Parkinson's disease and the role of the Parkinson's nurse specialist have been the foci of research. Australian literature related to speech therapy and Parkinson's disease has been predominately meta-analysis of treatment modalities. Literature dating back to the classic descriptive study by James Parkinson in 1817 documents the impact of Parkinson's disease on communication. However a void in the literature and subsequent insight into the potential impact of the communication changes has been identified. This deficit is the impact of communication changes on the partner of the person with Parkinson's disease. This research will address that gap in understanding and will highlight the recommendations for further practice.

CHAPTER THREE

Methodology

Introduction

This study utilizes a phenomenological approach. In essence, this interpretive method is suited to the exploration of the lived experience of partners of people with Parkinson's disease who demonstrate communication changes. This chapter will explore the rationale for this choice of methodology. The methods of selection of participants will be described and a profile of participants outlined. The method utilized to analyze the data extrapolated from the interviews will be explained. The necessity for the researcher to acknowledge existing interest in the disease process and care of the family unit affected by Parkinson's disease is outlined. Limitations of the study will be discussed in addition to ethical considerations for a study interpreting the lived experience of the partners of people with Parkinson's disease who demonstrate communication difficulties.

The Qualitative Paradigm

The goal in research is to describe, explain, predict and control the phenomenon under review (Burns & Grove, 2001, p. 75). Prior to initiating a study, the researcher must identify an appropriate methodology. That choice must take into consideration the diversity of quantitative and qualitative research methods. There remains a qualitative– quantitative divide which must be explored prior to finalizing the choice of method best suited to the study under consideration. Madjar (2002) acknowledges the necessity for randomized controlled trials but reinforces that clinical practice is not confined to statistical outcomes alone. She emphasizes that clinical practice is about complex individuals living in all types of relationships and experiencing despair and loss of control (p. 7). Thus the choice of methodology must reflect the topic under examination.

Quantitative research, such as the controlled trials discussed by Madjar (2002), places the emphasis on an empirical approach and emphasizes deductive reasoning, the rules of logic and measurable attributes of the experience (Polit & Hungler, 1993, p. 19). Quantitative methods can be said to make the assumption that the social world lends itself to objective forms of measurement (Leininger, 1985). The precise measurements, replicability, prediction and control utilized in quantitative research are vital when aiming to test, predict and control (Powers & Knapp, 1990, p. 120).

Qualitative research has earned respect in the scientific community for its potential to illuminate personal meanings. From the utilization of qualitative research as a methodology the rich knowledge about health care issues and practice is obtained (Rowe & Mc Allister, 2002). Real life intrudes into the idealized models for research methods (Rice & Ezzy, 2000, p. 6) and the use of qualitative research makes sense of and gives meaning to real life as described by the participants taking part in the study. Qualitative methods allow the exploration of human experience in ways that promote understanding of, and insight into social situations. The various types of qualitative research involve description and interpretation of human experience in order to promote understanding about and perceptions of social situations (Powers & Knapp, 1990, p.116). This approach to research, according to Denzin and Lincoln (1994), is multi-method in focus and involves a naturalistic approach to its subject matter.

If the nature of the research question demands a description of the topic studied then a qualitative study must be considered, as opposed to a quantitative study which demands a comparison of groups or a measurable method of study (Cresswell, 1998, p. 17). The purpose of phenomenological inquiry is to explicate the structure and essence of the lived experience of a phenomenon in search for unity of meaning which allows for identification of the essence of the phenomenon in everyday practice (Rose, Beeby & Parker, 1995).

Communication between partners remains a phenomenon which defies objective measurement and therefore can only be described. Communication between long term partners is the essence of a relationship and demands a humanistic approach when it is scrutinized. When communication between partners is affected by a progressive neurological condition such as Parkinson's disease the impact can only be described by those affected.

The qualitative facet of research provides us with the capacity to explore, in a rigorous empirical way, human experience that necessitates understanding of its wholeness and contextual situation (Madjar, 2002, p.7). For the reasons outlined I chose to utilize the qualitative approach within the interpretive, inductive paradigm to explore the experience of the partners of people with Parkinson's disease who demonstrate communication changes.

Phenomenology

The chosen methodology for this study is the phenomenological approach. This approach was chosen because it describes the meaning of experiences of a topic for several individuals (Cresswell, 1998, p. 236). Phenomenology, as described by Merleau Ponty (1962) and cited in Streubert and Carpenter (1995, p. 30) is: "the study of essences" and is therefore suited to exploring the essence of communication between partners. Phenomenology is a way of thinking first described by European philosophers. Edmund Husserl (1859-1938) first utilized phenomenology as both a philosophical tradition and a methodology. He followed the lead of his teacher Brentano to reform philosophy to a rigorous science given to serve the best interests of humanity. It is to Husserl that we credit the introduction of *Lebenswelt*, or life experience. For this reason in phenomenological research we ask the question "What is it like?" (Powers & Knapp, 1990, p.106). Husserl's most basic philosophical assumption, as described by Patton (1990), was that we could only have knowledge of what we experience by attending to those perceptions and experiences that awaken our conscious awareness. According to Becker (1992, p. 7): "Phenomenologists study situations in the everyday world from the viewpoint of the experiencing person." Phenomenology therefore focuses on how we put together the phenomena we experience in such a way to make sense of the experience and develop a global viewpoint. The value of phenomenology is that it focuses on the essence of shared experience. These situations must then be explicated and interpreted by the researcher.

Phenomenology is a natural choice for those nursing researchers who seek to illuminate world views. Many nursing theorists adopted this method to study the complexity and uniqueness that is caring in nursing (Benner & Wrubel, 1989; Cohen, 1987; Watson, 1979).

In clinical practice, Irvin (2000) chose phenomenology to interpret the experiences of nurses caring for terminal patients in nursing homes. The experiences of patients living with chronic

renal failure and undergoing renal dialysis have been explored utilizing the phenomenological approach (Martin- McDonald, 2003; Rittman et al., 1993; Whyte & Grenyer, 1999). The phenomenological method is based on interpretation and goes from naïve to profound understanding through explanation of the text and was the methodology of choice in a recent study into the experiences of older Swedish women living with Parkinson's disease (Caap-Ahlgren, Lannerheim & Dehlin, 2002).

Phenomenology is suited to nursing research because it offers a methodology that brings forth findings that are both intimate and complex. The meanings extrapolated from the data cross the boundary between everyday practice and human interaction. Phenomenology allows the nurse to reflect on the meaning of the subject and “offers a way to the soul of nursing” (Madjar & Walton, 1999, p. 3).

Madjar and Walton (1999, p.8) describe phenomenology as a bridge between stories of individual experience and the phenomena of human experience. This explains its appeal to nurses who are familiar with linking the individual experience and human experience in every day clinical practice. It was for this reason that I chose this sensitive methodology to explore and understand the experiences common to partners of people with Parkinson's disease who demonstrate communication changes.

Communication between life partners is the distillation of a long-term relationship and warrants an approach that is sensitive to the experiences of the partners. This level of communication is not a quality that can be measured on a scale, such as blood pressure, or timed, as in the case of mobility. In this study the shared experience is the impact of communication difficulties related to Parkinson's disease and their effect on the partner of the person with this progressive neurological condition.

Participant Selection

Five partners of people with Parkinson's disease participated in this study. Sample size in qualitative studies is dictated by several factors. It is vital to a qualitative study that it focuses in depth on those selected for their intimate knowledge of the topic under review (Patton, 1990, p.169). This is known as a purposive sample. It is appropriate in phenomenological studies to use a small homogeneous group to elicit common shared meanings of their lived experience.

Cresswell (1998) discusses the appropriateness of “criterion” sampling in a phenomenological study (p. 118). It is essential that all the participants have experience of the phenomenon. It can be argued however that purposeful sampling may present a biased viewpoint of the phenomenon under review (Cresswell, 1998, p.111). However purposeful sampling as outlined by Patton (1990, p.182) “selects information rich cases for in-depth study”. Information rich cases are those from which the researcher can learn a great deal about the central topic.

In phenomenological studies the researcher works towards theoretical saturation which is the point when data collection does not reveal new information (Powers & Knapp, 1990, p. 116). Rice and Ezzy (1990) define this as additional data which is repetitive and not leading to a new understanding (p.81). The size of the group is also influenced by the eventual repetition of information that does not yield new information (Hungler & Pollit, 1993, p. 333).

It is often difficult to determine in advance the number of informants or participants required for a study (Woods & Catanzaro, 1988, p. 135) because the sample size in a study utilizing the phenomenological approach is defined by the point of saturation. The data resulting from interviews with five partners of people with Parkinson's disease who demonstrated communication changes resulted in saturation and thus the sample size for this study was determined.

In addition to a purposeful sample being limited in size once saturation is reached it is necessary for the participants to be a homogeneous group. Homogeneity is defined by the Oxford Dictionary (1987, p. 510) as “being of the same kind”. It is clear that in order to explore the lived experience of a group of people experiencing a common phenomenon then it is the phenomenon which is homogeneous rather than the people who experience it. Woods and Catanzaro, (1988, p. 112) confirm this by explaining that if the parameter being studied is quite homogeneous then there is no need for a large sample group. The homogeneity of partners of people with Parkinson's disease demonstrating communication changes is a parameter that does not necessitate a large group of participants.

Procedure for recruitment of participants

The Research Committee of Parkinson's Western Australia (PWA) was approached for permission to advertise for recruitment of potential participants. Written permission was sought from the Research Committee PWA prior to placing an advertisement (Appendix A) for participants in the Association's bi-monthly newsletter. This advertisement requested that partners of people experiencing the impact of communication difficulties related to Parkinson's disease contact the researcher by telephone. The researcher was identified in this advertisement as a Master of Nursing Candidate of Edith Cowan University, Western Australia.

The criteria for participation in this study were: Participants were to be married to or a partner of a person with Parkinson's disease who demonstrated communication difficulties. These participants would identify the presence of communication changes. The participants would reside in, or be staying in, the Perth Metropolitan area of Western Australia. The main language for the participants would be English. The five participants in my study met these criteria. In addition to those who volunteered to be in the study as a result of the advertisement, there was one volunteer who wished to describe his wife's loss of memory rather than communication changes. As this volunteer did not meet the criteria he was not included in the study.

Four of the study participants responded to the advertisement by telephone and were subsequently posted a letter outlining the purpose of the study. This letter was also a consent form (Appendix B) which was returned to me utilizing the pre paid pre-addressed envelope. Confirmation of agreement to participate in the study was considered valid once the consent form was signed and returned. The remaining informant who volunteered to be a participant in the study was on vacation in Western Australia from South Africa. She became aware of the study in the course of my nursing assessment of her husband. She expressed a desire to participate in this study and she also signed a consent form.

Each participant received a copy of the consent form at the time of interview. In the event of any queries relevant to the study rising in the future each participant was given my contact details. The issue of confidentiality and the freedom to withdraw from the study at any time were addressed in the consent form.

Participant Profile

The participants in this study were all female. The gender of the participants was not purposeful but was a random result of a response to the advertisement for recruitment. Four of the participants had been married to their husbands for over thirty years and one for eleven years. The age range of the participants was fifty-two to sixty. Two of the five participants were retired nurses and one is currently employed as a nurse. One participant, who had responded to the advertisement while her husband was alive, requested that she continue in the study following the death of her husband. The researcher clarified this request with the supervisors and it was decided to include her in the participants as her interview data was relevant to the purpose of the research study. In addition it was deemed that participation in the study could have a therapeutic value and therefore it would have been unethical to refuse her participation. Four of the participants lived in the Perth metropolitan area and the remaining participant was on vacation from South Africa.

Interview technique

The interviews, which were audio recorded, took place in venues acceptable to the participants and accessible to both participant and researcher. These included for one interview the home of the researcher, for another an office used by the researcher in the locality of the participant's home and the remaining three took place in the homes of the participants. The interviews commenced after confirmation by the participants that they understood the research question and the format of the interview. The participants were aware that they could cease the interview process at any time if they felt uncomfortable with the content or proceedings.

The technique chosen for data collection was unstructured in-depth interviews involving the participant and the researcher. Minichiello, Aroni, Timewell, and Alexander (1995) define this form of interview as:

“ A conversation between a researcher and informant focusing on the informant's perception of self, life and experience, and expressed in his or her own words. It is the means by which the researcher can gain access to, and subsequently understand, the private interpretations of social reality that individuals hold” (p. 61).

Significant rapport already existed between four of the participants and myself because of prior contact through my clinical work. As a result of this the format of the interviews was non-threatening and relaxed. My role of Parkinson's Nurse Specialist was the rationale behind the advertisement in the PWA newsletter not stating my name as this may have been seen as coercion to participate. The participant from overseas also verbalized her ease with the interview process.

According to Minichiello et al., (1995) rapport with another person is a matter of understanding their world and communicating that understanding. This can be achieved by harmonizing and matching common interests between the researcher and the participant. In addition to the participants' awareness of my interest in Parkinson's disease, I utilized several social and welcoming methods, such as, thanking the participant for their willingness to take part in the study, the provision of liquid refreshments and a practice run with the audio recording equipment. I explained to the participants that in the event of emotional distress resulting from participation in the study they could be referred to the counseling services of the Neurological Council of Western Australia. Once both participant and researcher felt comfortable then the interview process began.

The interview commenced formally once understanding of the purpose of the research was confirmed. The participants were advised that they could stop the interview or switch off the recorder at any time they wished.

The interviews lasted between one and a half to two hours and a guide of prompt questions was available for use if necessary (Appendix C). The use of a prompt guide is to jog the memory of the researcher (Minichiello et al., 1995). In the interviews conducted for this study the use of the prompt guide was not necessary. The recorded tapes were then transcribed verbatim. The typist agreed in writing to maintain confidentiality of the information disclosed by the participants (Appendix D). As an additional means of ensuring confidentiality each participant was allocated a pseudonym which is used in this thesis to differentiate between the participants' quotes.

Observational field notes were made immediately following each interview to document non-verbal cues and subjective descriptions of the interview. These provided insights to the

emotional and social environment of the participants. Field notes describe that which has been observed during the interviews as nothing should be left to memory (Patton, 1990, p.239). Information from both the verbal and non-verbal sources assisted the researcher in data analysis. It is the field notes that enable the researcher to revisit the interview when reading the transcript.

Data Analysis

The data generated from the interviews with partners of people with Parkinson's disease who demonstrate communication difficulties resulted in voluminous verbatim transcripts. The purpose of data analysis is to preserve the uniqueness of each lived experience of the phenomena while allowing an understanding of the subject itself (Parse, Coyne & Smith, 1985). The process of analyzing the data resulted in the themes and sub themes described in later chapters.

I utilized the steps based on Colaizzi's method of phenomenological analysis, which has been outlined by Streubert and Carpenter (1995, p. 75). This framework follows the Husserlian tradition of phenomenological methodology. These procedural steps were:

1. Listening to the recorded tapes to confirm the accuracy of completed verbatim transcripts;
2. The transcripts were read several times to enable the researcher to achieve a sense of the whole. This step was repeated until a sense of familiarity was obtained;
3. Significant phrases and statements were identified and extracted from the data. These statements were directly related to the phenomena under study;
4. From these statements and phrases meanings were extrapolated and grouped into sub – themes;
5. Sub themes were clustered into themes; and
6. An exhaustive description of the phenomenon was written integrating the significant statements, sub -themes and themes (Colaizzi, 1978).

The themes, sub themes and definitions extrapolated from the data are outlined in Figure 1 overleaf. I identified the themes from the interview material and they were validated by my supervisors as being true to the data available. Each following chapter will address one major theme and its sub themes. As an introduction to each chapter the theme to be discussed will be

represented in a figure which includes the definition of the main theme, the associated sub themes and definitions of sub themes

Themes	Definition of Themes	Sub-themes	Definitions of Sub-themes
Partner-Carer Interface	The melding of the roles of partner and care giver	<ul style="list-style-type: none">• Point of Diagnosis• Life before Diagnosis• Sharing the Disease.	<ul style="list-style-type: none">• The Pivotal Moment• The strength or weakness of communication before diagnosis• Plurality of diagnosis
Emotional Turmoil.	The clash of emotions resulting from communication difficulties	<ul style="list-style-type: none">• Confronting the Physical• The Condition always wins.• Social Isolation	<ul style="list-style-type: none">• Acknowledging the physical changes due to Parkinson's disease• A loss of control• A lack of contact from within and outside the partnership
Ways of Coping.	Skills and mechanisms used in dealing with the impact of communication changes	<ul style="list-style-type: none">• Share the Burden• Know the Beast• The Road Ahead.	<ul style="list-style-type: none">• Seeking out company other than the person with Parkinson's• Seeking out Information• Preparing for the future

Figure 3:1 Themes, Sub themes and Definitions

Rigour and Trustworthiness

Qualitative inquiry, as described by Patton (1990, p. 183) is “rife with ambiguities,” so it is imperative that each researcher addresses the issues of credibility and validity within the sensitivities relevant to their study. Rice and Ezzy (2000, p, 257) state that rigorous qualitative research is trustworthy. They advocate the use of rigour rather than credibility as rigour focuses on meanings and their interpretations. In order to address these issues I have described how I utilized a variety of methods to demonstrate rigour in my study on the experience of the partners of people with Parkinson's disease who demonstrate communication changes.

Rigour or trustworthiness of qualitative research has been the subject of much literature (Brink, 1991; Guba & Lincoln, 1989; Koch, 1994). It has been argued that the transfer of validity criteria from the quantitative to qualitative paradigm is inadequate (Bailey, 1997; Sandelowski, 1986). However, the outcome of examining means of testing the phenomenological approach is that every experience is unique and truth is viewed as relative (Sandelowski, 1986 p. 29). Trustworthiness, or rigour, is important not only because it ensures the scientific value of a study but in addition it is only when a study is rigorous and well designed that the outcome can be a foundation for positive change (Rice & Ezzy, 1999, p. 29).

Credibility, or truth-value, can be described as faithful descriptions of the phenomenon. Lincoln and Guba (1989) identify credibility, transferability and dependability as the hallmarks of good qualitative research. Trustworthiness in qualitative research is measured using these criteria.

Faithful descriptions and interpretations of the phenomenon represent credibility. The phenomenon must be readily recognised by those who have experienced it or recognised by those exposed to it through clinical practice or reading about the phenomenon. Prolonged engagement with the phenomenon leads to increased credibility or trustworthiness of the study. My involvement as a Parkinson's Nurse Specialist adds to this prolonged engagement and thus to increased trustworthiness. This closeness is demonstrated by my position as Parkinson's Nurse Specialist and the role of interviewer during data collection. Sorrel and

Redmond (1995) explain that there exists a dual effect when conducting a phenomenological interview. The interview and the interviewer are intertwined. Sandelowski (1986), on the other hand, states that the close proximity of the researcher to the participant and the subject matter is a significant threat to credibility. A counter response to this could be that the closeness of the researcher to the subject matter has the potential to sensitize the data not sanitize it. (M.Langridge, personal communication, July 25, 2001).

The return of the analyzed data to the participants is one method often used for member validation (Sandelowski, 1993) however this is not always possible (Koch, 1994). The choice whether or not to return to the participants for validation lies with the researcher. Sandelowski (1993, p.5) argues that in her experience the participants are not interested in the abstract syntheses involving other participants but rather are only interested in their own experience.

For the purposes of my study I decided not to use this method of confirming validation because the information was time relevant and the sadness expressed by the participants at that time would not be relieved by revisiting the interview. The interactions could be described as being so unique that observations can only have meaning in the situation in which they occurred (Guba & Lincoln, 1981, p.116).

In my study validity was enhanced through supervision: There is always a need in research for colleagues, peers, mentors and 'friends willing to act as enemies' who can challenge and shock one out of habitual ways of thinking and experiencing (Reason & Rowan 1981, p.247). My supervisors acted in this role by reading the transcripts, challenging me and encouraging me to revisit the data. Their confirmation of the themes and sub themes drawn from the data was further assured by the validation of the study data sets and interpretations. In addition, the discussion resulting from the data derived from the interviews was read by a fellow Parkinson's disease nurse specialist. Her confirmation of the experiences and themes derived from those experiences as being similar to those evident in her clinical practice added to the validity of the study. This is often referred to as auditability:

Auditability requires simply that the work of one evaluator (or team) can be tested for consistency by a second evaluator or team, which after examining the work of the first can conclude, 'Yes, given that perspective and that data, I would probably have reached the same conclusions' (Guba & Lincoln, 1981, p.24).

The concept of transferability is also utilized as a method of demonstrating trustworthiness or credibility. Transferability refers “to the probability that the findings of the study have meaning to others in similar situations” (Streubert & Carpenter, 1995, p.26). To assess transferability the findings of my study have been discussed in clinical practice with six partners of people with Parkinson's disease with similar manifestations. These clients agreed that their experiences were common to those expressed by the participants in my study. This transferability continues within my role as Parkinson's Nurse Specialist.

Bracketing

Crotty (1996) acknowledges that it is impossible for qualitative research to be completely objective, as total objectivity is not humanly possible. It is for this reason that a researcher utilizes bracketing to identify researcher bias and preconceptions about the data.

Bracketing is a term first utilized by Husserl (1931). Bracketing is the means by which the researcher endeavours not to allow personal assumptions or knowledge to affect the interview process, data collection or analysis (Crotty, 1996). It has been described as the first step in phenomenological reduction, the process of data analysis in which preconceived experiences are laid aside in order to understand the experiences of the participants (Moustakas, 1994).

Ahern (1999) discusses in length a logical timeframe in which to address one's personal feelings and preconceptions. This time frame includes preparation, current and post analysis reflection.

In my study it was clear that prior knowledge and an interest in Parkinson's disease must be acknowledged. I have had an interest in Parkinson's disease for the entirety of my nursing career, thirty-six years, and for the three years prior to the study that I had been working in this area as a Parkinson's Nurse Specialist. During the data collection phase I was aware of and acknowledged an interest in the impact of all aspects of communication changes on both patient and partner. While this interest and prior knowledge of Parkinson's disease is due to my position it does not match the lived experience of those living with a person with the condition.

The researcher will always hold the etic (outsider's) viewpoint while the participant will forever present the emic (insider's) perception of the phenomenon. During the reporting phase it was

necessary to decide whether to follow the suggestion of Porter (1993) that the researcher's use of the third person reflected an assumption of objectivity. I decided that having addressed my interest and professional closeness to the topic that I would utilize the first person when writing the study.

Limitations of the study

While much insight into the experiences of partners of people affected by communication difficulties as a result of Parkinson's disease has been achieved from this study there are without doubt limitations to any study. The sample group was comprised entirely of female partners. It was not planned that the study would be gender specific and the inclusion of males may have provided additional data and therefore additional themes. Further research with a group of male participants may identify a diversity of experiences and allow for comparison.

The study relied on data collected from interviews and although care was taken to address any limitations arising from the method of collection it must be acknowledged that interview techniques can be seen as limiting. The number of subjects interviewed in qualitative studies is limited and therefore it must be remembered that this study will not result in an outcome which can be generalized. The purpose of a phenomenological study is to explore the feelings and experiences of a number of people who are experiencing the subject, not to apply the experience of this group of people to a greater population.

The role held by the researcher could be seen to be a limitation but with the awareness of preconceptions and the utilization of bracketing the potential for lack of objectivity was addressed as best as possible.

Ethical Considerations

Written permission for this study was granted by the Committee for Conduct of Ethical Research Involving Human Subjects at Edith Cowan University. Permission was also granted by the Ethics Committee of Parkinson's Western Australia.

As previously described informed written consent was obtained from the participants prior to commencement of the interviews. The participants were informed that they could withdraw from the study at any time. Research data will be kept for a period of five years under lock and key in my home then destroyed by incineration. The audiotapes will be erased after completion of the research. Those persons having access to the data are myself (the researcher), the designated supervisors and the professional typist.

Conclusion

This chapter has explored the rationale for the choice of methodology and described the steps taken to undertake the study of the lived experience of those partners of people with Parkinson's disease who have communication changes. Phenomenology offers the researcher the chance to study human experience in the life-world (Madjar & Walton, 1999). This method of study offers nurses the opportunity to observe, hear and relate to the narrative that has been previously unsaid. As one participant stated during her interview: *Use this study to answer the questions we don't know to ask (Debbie)*. This qualitative study will result in richness of data that will meet such a request.

The interviews with partners of people with Parkinson's disease who demonstrate communication changes resulted in a wealth of data regarding their experiences. An analysis of interview content uncovered three major themes: The Partner-Carer Interface, Emotional Turmoil and Ways of Coping. These themes were identified as having particular meaning for the study participants. Each of the following chapters will discuss a major theme and the associated pertinent sub themes. The findings will be discussed in relation to literature. Direct quotations from the participants will be identified by the use of italics. Each participant has been allocated a pseudonym to ensure confidentiality and where the participants used the name of their partner the name has been substituted by [spouse].

CHAPTER FOUR

The Partner-Carer Interface

Introduction

The first major theme to be identified has been titled the Partner-Carer Interface. This Partner-Carer Interface is defined as the melding between the roles of partner or, as in the case for each of the participants, wife and caregiver. Despite the initial request for participants to be involved in the study as the partner of a person with Parkinson’s disease and the research question referring to the lived experience of the partner of a person with Parkinson's disease, it became evident quite early in each of the interviews that each participant referred to herself as a carer rather than a partner. An extensive search of the literature pertinent to Parkinson's disease was unable to reveal previous reports of this phenomenon. The necessity for the partners to modify both their partner role and the carer role highlights the challenges inherent in the overlap of role perception and attribution. The shift in role was described by the participants as both a gradual process and a definitive point in time depending on the progression of the disease process and the individual manifestation of symptoms. Outlined below in Figure 2 is the major theme and associated sub-themes discussed in Chapter 4.

Theme	Definition of Theme	Sub-themes	Definitions of Sub-themes.
Partner-Carer Interface	The melding of the roles of partner and care giver	<ul style="list-style-type: none">• Point of Diagnosis• Life before Diagnosis• Sharing the Disease.	<ul style="list-style-type: none">• The pivotal moment• The strength or weakness of communication before diagnosis• Plurality of diagnosis

Figure 4:1 Partner-Carer Interface

Role identity and confusion

The role of a partner, or spouse, is multifaceted and marriage is found in all cultures. Marriage, among other relationships, when successful is a source of great joy, satisfaction and good mental and physical health (Argyle, 1991, p. 16). The author goes on to state that communication, both verbal and non verbal, is a vital aspect of this relationship. When couples interact their roles are closely linked to their self image and in turn their identity (p. 20). Beeson (2003) confirms the role of marriage in meeting human needs. Sharing life experiences with a spouse over a lifetime helps to define and maintain one's individual need for human, interpersonal intimacy in addition to defining who we are as individuals and partners (p. 141). It is the interchange of identity reported by the participants in my study which is the focus of the first major theme. The melding of the role of partner into an involuntary role of carer became evident through the interviews. There was, in addition, some degree of confusion regarding which role was the predominant one at the time of the interview. *It is terribly confusing for the carer or partner or whatever I am (Beth).*

The confusion expressed by the participants in this study may be explained by the communication changes resulting in a variety of needs unlike those normally associated with caring. The role of carer, or caregiver, is usually associated with the provision of physical assistance necessary to carry out routine activities of daily living and is not solely confined to the spouse or long term partner. Leinger's definition of caring is cited by Marriner -Tomey (1994) as "referring to actions directed toward assisting, supporting or enabling another individual with ...needs to ameliorate or improve a human condition" (p. 429). The commonly accepted acts of care-giving are those relating to activities of daily living such as showering and dressing. In the experiences of the participants in my study they were required to assist their partners with acts of communication such as writing, speaking or making decisions. The impact of Parkinson's disease on communication can mean that a partner must assume tasks other than those normally considered as part of the role of a carer. These tasks can include answering the telephone and interpreting unclear speech or handwriting. It is only with hindsight and considerable thought that the participants identified the assumption of the role of carer.

I think it's such a gradual process that you don't realise that you are a carer but I think because I started to write for my husband and then to talk for him, probably sooner than most other people with Parkinson's have to, you know sooner than other carers do. I didn't see that talking and writing for someone wasn't the typical caring sort of thing you did (Amy).

The participants in the study continued to refer to themselves as carers throughout the interviews in spite of the emphasis of the study on the exploration of their experience as partners. *I am his carer now, much more so than his wife (Eve).* This reluctance to identify themselves as partners may have been a response to the emotional and personal impact of the shift in role perception. The conflict resulting from the shift in role is experienced at a deep and personal level of which the participants may not be consciously aware. Festinger (1957) described this response to disequilibrium or discomfort as cognitive dissonance. Festinger's theory is that tension results when people realise that there are inconsistencies between their beliefs and their outward actions. One strategy identified by Festinger and Carlsmith (1958) to reduce the dissonance is that in order to restore comfort or harmony attitudinal changes are introduced. The person changes his or her thought patterns in order to bring them into correspondence with what they are verbalizing. This would explain the self described carer role when the opinion of the partner was requested. The diminished state of the partnership resulting from the impact of communication changes caused discomfort or disequilibrium and therefore it was less confronting for the participants to readjust their perception of their role to that of carer. It can be hypothesised that the role of carer, in the minds of the participants, is less emotionally involved and in turn less painful. Huffman, Vernoy and Vernoy (1994) differentiate cognitive dissonance from rationalisation by acknowledging that the function of cognitive dissonance is to reduce conscious inconsistencies, thereby bringing about a change in attitude (p. 629). Egan (1986) reminds those working in helping professions that clients react to cognitive dissonance by running from topics that are too painful. He emphasises the need for an accurate, sensitive understanding of their feelings and behaviour (p. 206). It was with my silent acknowledgement of their personal adoption of the carer role that the interviews continued.

The participants reflected on the timing of the shift in their role from partner to carer. The progression of Parkinson's disease, the subsequent impact on communication and concerns for the future seem to have clouded the perceptions of the participants as to when the transformation from partner to carer was identified. *I was probably a carer before I realised it (Eve).* It is possible that the subtleness with which the disease process ensued leads

to this uncertainty which appears to be ongoing for the participants. Another participant echoed this sentiment. *I really feel that I am a carer at the moment, even more than a wife (Debbie).*

Despite an awareness of the progressive nature of the disease and the melding of roles this participant expressed the hope that her role would revert to that of wife at some stage. *I hope that I can get back to being a wife again (Debbie).*

The participant in my study whose husband experienced a sudden loss of speech related to a necessary surgical intervention defined the onset of the caring role as the time of her husband's increased physical needs rather than the point when communication became difficult. *I became a carer when my spouse started physically to need me much more. Before that it was purely partner (Colleen).* Yet another participant related the timing of her role change as coinciding with a change in her spouse's medication regime. The admission that a partner identified the assumption of the caring role with a change in medication regime is a reminder that medications and the efficacy of the medication regime have a huge impact on all affected by Parkinson's disease, both patient and partner.

When I became a carer would have been about six months ago. The last time [spouse] went into hospital, when they changed his medications. Then I became a carer and it hasn't really improved since then, in fact it has at the present got worse (Debbie).

The participants identified that the assumption of the role of carer was a natural progression from their role of partner. Each participant acknowledged the tendency for a wife to assume the role of carer as a natural extension of her marital role. The role of carer is not always identified as a positive outcome of the responsibility of a partner. *Life as a carer is restricted and I suppose that's not what I imagined when I got married (Debbie).* This added dimension augments the interface between the role of partner and carer. Another participant's comments supported and identified the extension of the role of partner. *Obviously a partner would just be a partner whereas a carer may be asked to go one step further (Beth).* Yet another participant acknowledged the progressive nature of the disease process with the passage of time. *The role of the carer becomes more encompassing (Amy).* The participants in my study identified that life did not allow them a choice in the role or the Partner-Carer Interface thrust upon them by Parkinson's disease. *I would say that I am a carer because I am automatically a partner as his wife. That is obviously without question (Eve).*

The recognition by the participants in the study that they are carers as an extension of their long standing partnerships is reinforced by the caring ideals and centrality of

caring in women's lives as identified by Wuest (1997). This grounded theory study implemented from a feminist perspective addressed the changes in current health services and the expectation for women in the community to fill the caring role. The 21 Canadian women interviewed by Wuest were caring for both relatives and partners with a variety of illnesses. The centrality of caring in women's lives was seen to be evident and was expressed as caring being a positive aspect of a women's nature and "fundamentally good" (p. 51). However relationship proximity between the caregiver and recipient was identified as a potential fraying connection as was the dissonance of varying degrees of emotional and relational challenges (p. 56). Wuest (1997) identified that professional support for the caregiver and mutual respect within that professional relationship will influence the women's caring capabilities and lessen the fraying connections. Recent studies into caregiver burden in those providing care for individuals with Alzheimer's disease and Stroke disease revealed that the caregivers were predominately females caring for their spouses (Beeson, 2003; Clark & King, 2003). A needs analysis of patients with Parkinson's disease in Central New South Wales revealed that 60% of those interviewed ($n = 69$) were female and 85% were married to the care recipient (Dunn & Hammond, 1999). These findings that females are more commonly involved in unpaid care provision are in agreement with world wide statistics. Thus the gender of all the participants in my study is not unexpected.

The uncertainty or confusion expressed by the study participants regarding their role is similar to the phenomena identified by Viney (1980, p. 10) who described the major transitions faced by 490 Australian women in their lifetimes. The transitions included in Viney's study were changes in education, finding a life partner, becoming a mother, illness and approaching death. The author asserts that women in transition initially see this transition as ambiguous. The ambiguity of the roles of partner and carer is the essence of the Partner-Carer Interface identified by the participants in my study.

The progressive nature of Parkinson's disease and its impact on the personality of the patient was the subject of a study by Mendelsohn, Dakof and Skaffs (1995). The authors studied the perceived personality changes in 41 patients using retrospective self descriptions. In order to corroborate the data from those interviewed the spouses of the patients were included in the study. In spite of communication not being addressed as a variable in this study the researchers concluded that the impact of Parkinson's disease is best described as a "process of adaptation" (p. 256). This process is not confined to the illness but includes the adjustment of

all aspects of life and specifically the evolution of a new set of relationships. The role change or adaptation of the spouses in the study by Mendelsohn et al. is not discussed but the development of new relationships and adaptation would support the interface between the role of partner and carer.

In contrast to the experience of the participants in this study, a publication by Parkinson's Society of United Kingdom, Parkinson's disease and the Nurse (1992) suggests that most people in the caring role do not recognise themselves as carers and are resistant to admitting to this status passage. In addition to the confusion of roles, the needs of partners or carers are prone to misinterpretation by those assessing the needs. The United Kingdom Parkinson's Disease Society Report (1998) in a survey of 2,500 members described the majority of carers as looking after a spouse or partner for an average of nine years. An assessment, by health professionals, of the needs of carers indicated that the most valuable interventions would be provision of expert advice about Parkinson's disease, the availability of treatment, and access to a health professional or doctor. The problems most frequently identified by carers, however, were psychological and communication difficulties.

The identification of confusion on the part of the participants regarding their role adds a new dimension to the provision of support given by health professionals from the outset. The Partner-Carer Interface demands that the partners be supported through that initial time when all concerned are adjusting to the role changes arising from the diagnosis and progression of Parkinson's disease. It is clear that the partners who find themselves transforming to the role of carers require support and informed information before and during this transition.

Point of Diagnosis

The first sub-theme under the main theme of Partner-Carer Interface was identified as the "point of diagnosis". This is defined as the pivotal moment when the world changes for both the person with Parkinson's disease and their partners. It is with hindsight that the participants identified their progression along the partner-carer continuum but it is the telling and manner of telling at the point of diagnosis which impacts more than the future implications for their role. All participants regardless of their personal experience disclosed that the actual point of diagnosis was a memorable moment. Each described the timing, method of telling and their

response to that catalytic moment. The actual telling of the diagnosis was seen to be a pivotal point which would always be revisited and analysed.

While the “point of diagnosis” was a life altering moment the immediate reaction was one of relief. This was an emotion shared by the participants. In this study the participants reported that they did not experience great shock at the diagnosis given to their husbands and in fact the diagnosis came as a relief because it gave a name to and an explanation for the changes observed. *It was a relief, because now we didn't have to make people try to understand his writing (Amy)*. Yet another participant stated: *I knew I was going to be given the answer to all the puzzling changes I had observed (Eve)*. A third participant expressed her feelings as follows:

I wasn't actually shocked. I was perhaps very surprised, sort of. But in a way I was thinking that explains all those neurological problems you know, the inattentiveness, lack of attention, trying to get attention, the communication breakdown (Beth).

For one participant, in addition to the initial relief, she experienced apprehension. She described her emotions with veracity and in strong terms.

I must be truthful. I was a little, afraid is not the right word, appalled is too strong because when you hear of Parkinson's you think of elderly folks with terrible tremors. Appalled is too strong a word. I suppose I was in shock, not shocked but in a state of shock (Eve).

In spite of the strong emotions and fears for the future experienced at the “point of diagnosis” the participants appeared to be unaware of the impact of the condition on communication or its potential effect on their relationship. The assumption of the role of carer at the point of diagnosis was not immediately identified as a reality.

I think if you had to know that you were a carer from the moment of diagnosis you would both go under because no one chooses to be a carer and it's a role that is thrust on you whether you like it or not. Some people buckle under with it and some see it as a challenge (Amy).

For the participant whose husband underwent an unexpected total loss of verbal communication subsequent to surgery the realisation that the communication changes were permanent was a gradual process. *It took a long time for me to realise that this was something that was going to be permanent (Colleen)*. She had already faced the initial diagnosis of Parkinson's disease and observed the progressive nature of the condition but the realisation of the nature of the most recent communication changes was not initially apparent.

For one participant the timing of the telling of the diagnosis seemed very unfair. We can surmise there is never a good time to be given a diagnosis which will be life altering but for Debbie the “point of diagnosis” came on their first wedding anniversary. This participant identified that from that point in time another identity was part of their marriage. *It was our first wedding anniversary present. We have always had a third person along with us. And that third person is Mr. Parkinson (Debbie).*

The participants in my study recounted their clear memories of the actual “point of diagnosis” and in their recalling that event it is clear that they did not consider themselves as carers at that time. Literature specific to Parkinson's disease and the telling of the diagnosis highlights experiences of the person with the condition. Dennis Greene, an Australian author and poet, cited in Blake-Krebbs and Hermann (2001), describes his reaction to his diagnosis at the age of thirty nine and in the absence of his wife. He assumes that this moment was also a pivotal moment for her:

That moment of diagnosis was for me one of those moments when the world shifts on its axis and nothing will ever again be quite what it was or where it was before. My wife had not accompanied me to the appointment. It was to be a few hours yet before she got to hear that carer had been added to her job description and her world too was moving in strange new ways (p. 26-27).

The reaction to the initial diagnosis is described again from the perspective of the person with the condition. Ivan Vaughan, a British academic, was diagnosed with Parkinson's disease at the age of thirty five. He recalls travelling home to his wife and apologising for the news. He acknowledges that their reactions were very dissimilar:

Neither of us knew what was involved. The uncertainty left Jan very disturbed and frightened, while I was casually dismissive determined to enjoy the challenge (Vaughan 1986, p. 4).

Kinsley, an American journalist, (2001 p. 56) describes denial as his reaction when he was diagnosed with Parkinson's disease at the age of 42. He rationalizes his reaction as being appropriate at a time when he felt that he deserved to act selfishly. He does not record the reaction of his partner to the diagnosis nor does he reflect on the role of his partner for the future they face together. Blake-Krebs and Herman (2001, p. 6) refer to the “point of diagnosis” as the beginning of a journey. The experiences recounted by the partners in my study show that this journey is not a lonely pilgrimage for the person with the condition.

The participants in this study identified that they are travel companions to their partners on the journey.

Corbin and Strauss (1984) investigated the management of chronic illness by couples working in collaboration. The authors are sensitive to the fact that chronic illness “catches real people in the midst of living their life” (p. 109). In depth interviews with sixty couples over a two year period revealed that in spite of the impact of a chronic disease the couples accept the limitations placed on them. Corbin and Strauss (1984) recognised that the main strength of the couples interviewed was their ability to “talk it over, to talk about it, and talk it through” (p. 112). However the couples facing Parkinson's disease must deal with the fact that muscle rigidity and bradykinesia can deprive people with the condition of 93% of their communication skills (Scott, 1998, p.4). The physical manifestation of these aspects of Parkinson's disease will make the ability to discuss their problems and challenges less likely. It is essential that health professionals working with patients and their partners at diagnosis are sensitive to these potential unmet needs.

Life before Diagnosis

While the journey to be travelled was seen to commence at the ‘point of diagnosis’ the interviews with the participants identified that their “life before diagnosis” was as important to the partners as the future they faced. This became the second sub theme extrapolated from the data resulting from the interviews. “Life before diagnosis” is defined as prior communication skills and their impact on the situation within which the participants and their partners find themselves.

In seeking to explicate their current role confusion the participants inevitably referred to their communication strengths and weaknesses prior to diagnosis and the onset of communication changes. The often historically well developed forms of communication can enhance or detract from the processes of adaptation to chronic illness. The participants in my study reported both effective and ineffective communication interactions as being features of their relationship with their husbands prior to diagnosis. The extent of the impact of the changes wrought by the disease process appeared to be dependant on the strength and quality of the pre diagnostic communication. The participant whose spouse had died prior to the interview recalled that even when speech was impossible for her husband

they attempted communication by other means. This desire to communicate was based on their past history of closeness and effective communication skills.

We were always a close couple. We still tried to communicate as much as we needed and wanted. We never stopped talking to each other or not saying because [spouse] made a point of writing things down (Colleen).

The closeness of the relationship prior to the diagnosis of Parkinson's disease and the ability to share experiences are regarded as firm foundations to equip the couple for the advent of a time when speech and verbal reminiscing is no longer possible.

We have shared so much in the past and we always have had such a good relationship, on all levels before that that can sustain us. We've got lots of good shared memories and we've had lots of good enriching experiences together. We have enough richness in our life that will probably keep on sustaining us because our kids are still around so a lot of that just doesn't need to be said. It is just unstated. I suppose we are lucky in that sense as a lot of people aren't so lucky. They haven't had a good relationship and had so many varied life experiences as we've had (Amy).

In contrast, another participant described her husband as previously being uncomfortable with communication. This reluctance to communicate preceded both their marriage and the diagnosis of Parkinson's disease. However because of her natural desire to communicate more effectively he made a conscious effort to overcome the difficulties related to his personality and in more recent times, Parkinson's disease.

When I married [spouse] he didn't talk about things. He never asked questions. He and his first wife didn't discuss things. He does now. Because he married me. Communication is not a great skill. He's known as a very quiet man. But when you get to know him he's not. You know he has an extremely wicked sense of humour. To outsiders he's a very quiet reserved man. I suppose communication was difficult for him and it is now (Debbie).

Yet another participant described communication difficulties as inattentiveness which was evident prior to diagnosis. It was with hindsight that she attributed this to the pre-existence of the disease.

The inattentiveness, lack of attention, trying to get attention, communication breakdown. Because I do feel that we don't have communication. We have difficulties in a communication breakdown. We have a communication problem. This is definitely related to Parkinson's disease. I might also add that the lack of communication does lead, or can lead to big marriage problems, yes. With Parkinson's disease there is a double problem if you like (Beth).

The diminishment of body language and facial expression in conjunction with reduced volume and unclear speech patterns resulting from Parkinson's disease leads to an incongruence between verbal and non verbal communication. For the participants this resulted in difficulty in interpreting a spouse's needs and feelings in

spite of prior closeness. They identified that assumption was often the tool used to clarify the message being sent by the person with Parkinson's disease.

Parkinson's was the last straw that broke the camel's back because now you have got almost a child and I am not demeaning him by saying child. I am saying you have to try and imagine if that child is thirsty or if they have a dirty nappy and you have to try to imagine how he is feeling. Is he frustrated? Is he depressed? Depression is very hard to see but I think with Parkinson's I think it is even worse (Eve).

Yet another participant relied on her ability to feel her husband's mood change rather than expect him to verbalise his feelings. Her immediate emotional response was to withdraw from his mood however, in spite of the lack of response, she continued to verbalise as she stated that this was her natural tendency in any situation. *If I feel he has withdrawn then I put walls up. But I am a communicator. I am a people person and I blab (Debbie).*

The ability to translate the masked expression of Parkinson's disease into a tangible request or message did not come naturally for the partner who had previously admitted that effective communication was not strength of their relationship prior to the diagnosis.

There's the deadpan expression. He wears a full beard so we are really talking about maybe high cheek bones up to the top of the forehead, which doesn't leave much of a gap for you to read. You can see by the eyes. But unless you are sitting there looking at each other's eyes you are not going to pick it up. I am still learning to do that (Beth).

The challenge of hypothesising on the needs of one's partner who demonstrates communication changes is likened to living in a guessing game.

Communication is a huge component of any relationship and obviously when a person dies there's a total loss of communication. Living with someone who can't talk is like living, playing a game of charades all the time where you are trying to tease out a key word. It is not a game though (Amy).

For this participant it was the strength of previous communication, or "life before diagnosis" that enabled her to play the game of charades with some success.

We have similar tastes in art and books and things like that. We started off on a fairly good ground but you know if we had a real fractious marriage in the first place, then it would be difficult. I think I know, having been married for so long, what he would think about certain things (Amy).

The ability to communicate depends on the quality of relationships and the quality of the relationships is in turn affected by the quality of performance as communicators. The issues of relationships and communication as outlined by Mackay (1998, p. 125) create a paradox. It can be conjectured that the issues of relationships and communication are interdependent.

Michael. J. Fox (2002), a well known actor diagnosed with Parkinson's disease at the age of 30, gives a personal insight into his rationale for minimizing his communication regarding Parkinson's disease with his wife. He defines his reluctance to discuss his health problems as a choice rather than a result of communication changes. The fear of discussing his diagnosis in turn led to a limitation on any communication between him and his wife:

If I can't fix it, I don't want to talk about it. As a personal doctrine this one is flawed, but carried into a marriage it is pure poison. Sadly, I thought I was doing Tracey a favour-after all there was no way she could do anything about my illness, so why burden her by talking about it? But with a problem so huge, *not* discussing it meant not discussing much of anything. Even small talk became risky, because who knew what bigger issues that could lead to? (p. 179-180).

Effective communication has long been proposed as the basis for any relationship. Mackay (1998, p. 127) outlines the link between insecurity in a relationship and difficulties in communication. He encourages the reader to view communication within a relationship as a vital factor in the ongoing process of maintaining the relationship. Silink and Silink (2000, p. 121) reinforce the importance of communication as a basis for a relationship by encouraging partners to identify and discuss their values. The sharing of these values encourages responses from the partner. It could be concluded therefore that any physical or cognitive impairment that impacts on communication will have a far-reaching effect on the partner of the person with the communication deficits.

Neufield and Harrison (1995) examined the reciprocity between 40 caregivers and care recipients in addition to that found in relationships with family and friends. The caregivers were all female, one group caring for premature babies who were unable to communicate verbally and the other group caring for elderly people with cognitive impairment. The latter group demonstrated limited ability to communicate. The participants in this American study were interviewed several times over an 18 month period. These caregivers identified that they utilised a process of observation in order to obtain evidence of interaction (p. 355). This observation process was combined with a reduced expectation of a clear response from the care recipient. This finding confirms the experience of the participants in my study who described the necessity of guessing or obtaining evidence of the needs or emotions of their spouses

The participants in my study raised the issue of the gender differences in communication. This observation was based not only on a gender communication variance but also interestingly based on one participant's comparison of her mother's manifestation of Parkinson's disease compared with that demonstrated by her husband. This phenomenon has not been expressly explored previously.

With my Mum there was no lack of communication. She could still talk, reason, get frustrated, plan, give advice, encouragement. She had it more physically. There is a difference between them. She was much better. My husband has retreated. He's just like a little shadow going from pillar to post you know (Beth).

For another participant the issue of gender variation in communication skills was a general comment. For this participant the explanation to communication changes was that perhaps the problem under discussion was not related solely to the disease process.

Maybe also don't you think that maybe women are better at communicating normally than men at the best of times? I mean even if your husband hasn't got Parkinson's disease sometimes it's like drawing teeth literally you know. Slowly, painfully and surely (Eve).

Coates, (1993, p.188) discusses the gender related variations in communication. These include responses and self disclosure as being less common phenomena in male conversations. It is also the opinion of Coates (1993) that males do not value the role of listening as highly as the females (p.192). The impact of Parkinson's disease on communication between partners will be felt to a greater extent if the findings of Coates' sociolinguistics are valid. The impact of this progressive neurological condition on the communication between husband and wife is best summarised by a participant. She acknowledges the far reaching effects of Parkinson's disease and the impact on all aspects of communication. *In a marriage where there is Parkinson's disease it intensifies communication problems tenfold. Parkinson's has affected our communication about 100 % (Eve).*

Sharing the Disease

This concept of "sharing the disease" was described by the participants in my study and therefore was identified as the third sub theme in the Partner-Carer Interface. "Sharing the disease" is defined as the plurality of the disease. From the "point of diagnosis" the partner and the person with Parkinson's disease are faced with a common foe.

At the onset, or "point of diagnosis", the foe is an unknown identity. The exact course and speed at which the Parkinson's disease will manifest is impossible to predict as no two people with Parkinson's are the same (Oxtoby, Williams & Iansek, 2002, p. 13). However,

the extent of the impact of Parkinson's disease is so far reaching that the person with the condition and their partner can soon assume a shared diagnosis. Clinical experience confirms this "sharing of the disease" as partners often quantify the length of time since diagnosis as.... "we were diagnosed in" or medications prescribed as ... "we take..." The plurality of the diagnosis was described by those participating in this study. *This is my disease as well (Eve)*. Another participant discussed the duality of the experience of the condition almost with a sense of ownership. *It's not just the patient, if you are married or a partner you are a team. It's not just the person's disease, it's the team's disease and it impacts on everybody. It impacts on me. Everybody. (Debbie)*. The co-ownership of the diagnosis is confirmed by yet another participant. *I often said to [spouse] it's not that you have Parkinson's disease and I am just your wife. I'm living your Parkinson's with you (Colleen)*. The plurality of the diagnosis is remembered even following the death of this partner's spouse.

The nature of communication as a two way process demands that if the process is interrupted there is an alteration in dynamics the impact of which will further the perception of sharing the disease. My participants' heartfelt descriptions of the impact of the communication difficulties were a revelation. However it should not have been unexpected. The concept of "sharing the disease" encompassed the effects of communication changes. The outcome of living with a person with communication changes was described by the participants as their metamorphosis into someone similar to their partner with the condition.

I have read that people, the spouses of people with Parkinson's become a little bit like their partners, And I can see why. Because you are not getting that lively feedback that social contact that makes people react you know. And that is quite a loss. I don't always realise what's happening to me until I go out with other people and I realise they are giving me feedback all the time. Or my kids come and I get feedback from them and all of a sudden I find I'm yapping to them you know. It's my world that's become very silent too (Amy).

The changes wrought by Parkinson's disease on non- verbal communication and specifically facial expression were identified by the participants as having a marked impact on their personal communication skills. This participant proceeded to describe the effect of her partner's paucity of facial expression as limiting her own ability to express emotions non-verbally.

If you don't get any feedback from a face then you think you are not registering with them. And then you don't bother. Your face stops registering interest, dismay, excitement, despair.... So you become rather blank yourself (Amy).

Amy had described one negative aspect of communication in Parkinson's disease as becoming a two way process just as unimpaired communication is a dynamic process.

Her simple but profound observation and experience is a vital lesson for health professionals dealing with those “sharing the diagnosis.”

Argyle (1991) describes the non verbal interactions between two people as the ‘gestural dance’ (p.178). He describes the interchange of gestures and expressions as being closely linked to speech and if two individuals are in personal rapport they mirror their posture and produce congruent body movements (p.178). This may explain the “sharing of the disease” in relation to communication changes as the partner may mirror the manifestation of the Parkinson’s disease.

The experiences of the participants living with partners with communication changes related to Parkinson's disease are confirmed by Greene (2000, p. 40-43) who describes her own experience of her husband Dennis’s eleven year history of Parkinson's disease. Mrs. Greene affirms that communication is a two way process and that human beings are naturally social creatures responding to a friendly face and body language. She likens communicating with a partner with Parkinson's disease as reading a closed book:

It is strange therefore to be faced with a person with whom we are trying to communicate, who responds with a blank look, very little or no body language and slow replies, or none at all (p. 40).

Greene concludes her observations on being the wife of a young person with Parkinson's disease by confirming the tendency described by Amy to reflect the body language displayed by people with Parkinson's disease. “Hard as it is we must not mirror their expressions. We have to make a conscious effort to be just as we usually would be” (p.43).

The impact of care giving on the emotional well being of the spouse providing care is well documented (Beeson, Horton-Deutsch, Farran & Neundorfer, 2000; Carnwath & Johnson, 1987). These studies demonstrate that there is a high level of loneliness and depression among care giving spouses compared to non care giving spouses however the impact of the loss of the ability to communicate non- verbally has not been assessed. A recent American study comparing the many outcomes of care provision by partners of people with Alzheimer’s disease and those affected by Stroke addressed such issues as fatigue, depression and help seeking (Clark, & King, 2003). In spite of loss of communication being common to both the conditions affecting the care receivers this aspect of the partnership dynamics was not assessed. Those interviewed did not identify that they felt that they were “sharing the disease” that had affected their partners.

Conclusion

The experiences of the partners of people with Parkinson's disease who demonstrate communication difficulties resulted in the early identification of an overlap or melding of roles. This leads to self-labeling as carers rather than partners. Resultant from the role dissonance the first major theme The Partner-Carer Interface was identified. With the diagnosis and progression of Parkinson's disease comes relinquishing and readjustment of roles for both the patient and the partner. The confusion and overlap of roles expressed by the participants in this study will add a depth of understanding to the holistic management of the couple facing a life altering disease process. The impact of a progressive disease process such as Parkinson's disease is experienced from the "point of diagnosis" onwards. This is the first sub theme identified from the data resulting from the interviews. The "point of diagnosis" will always be remembered as a pivotal moment in time. However for the participants in my study this pivotal moment in time was not the point where they transformed into carers.

The participants, while recognizing the ongoing impact of communication changes arising from Parkinson's disease, each described their ability to adjust as being based on the communication strengths or weaknesses they had shared with their partners prior to the present situation. This was defined as "life before diagnosis" and is the second sub theme extrapolated from the in depth interviews with the participants in this study. The closeness of their past relationships enabled the partners to project or presume the physical needs and emotional state of those affected by the disease.

The participants each confirmed that the diagnosis of Parkinson's disease given to their partners impacted on them to the point where they felt that they too were living with a diagnosis of Parkinson's disease. This phenomenon was identified as the third sub theme, "sharing the disease." The commonality of the diagnosis was not solely related to the level of care-giving necessary or the lack of interaction but was seen to be more personally insidious. The paucity of facial expression, gesture and verbal interaction resulted in a similar lessening of non verbal and verbal communication skills in the partners. The lack of interpersonal communication was felt to be responsible for loss of skills previously enjoyed by the participants. Such depth of perception from the participants regarding their own

communication skills being adversely affected by the changes seen in their partners demands further exploration.

The following chapter will explore the second major theme of the Emotional Turmoil experienced and described by the participants living with partners with Parkinson's disease who demonstrate communication changes.

CHAPTER FIVE

Emotional Turmoil

Introduction

The commonality of emotions such as anger, frustration, sadness and regret and the internal conflict associated with these emotions led to the development of the second major theme. The major theme experienced by the partners of people with Parkinson's disease who demonstrate communications changes is identified as Emotional Turmoil. This theme is further explored in three sub-themes: “confronting the physical”, “the condition always wins” and “social isolation”. This chapter will present and discuss this theme and sub themes as revealed in the participants’ interviews. Pertinent literature will be discussed in relation to the findings of this study. Outlined below in Figure 3 is the second major theme and associated sub-themes.

Theme	Definition of Theme	Sub-themes	Definitions of Sub-themes.
Emotional Turmoil	The clash of emotions resulting from communication difficulties	<ul style="list-style-type: none">• Confronting the Physical• The Condition always Wins• Social Isolation	<ul style="list-style-type: none">• Acknowledging the physical changes due to Parkinson's disease• A loss of control• A lack of contact from within and outside the partnership

Figure 5:1 Emotional Turmoil

Emotional Turmoil

The emotions experienced and described by the participants in my study were common to all and resulted in similar expressions of Emotional Turmoil. This major theme, Emotional Turmoil, is defined as a confusion of feelings, such as anger, frustration and guilt, on the part of the partners resulting from the communication difficulties or changes due to Parkinson's disease.

For the majority of the participants this was the first time they had verbalized these feelings of anger, frustration and guilt, and it was acknowledged as a cathartic experience. *I have never expressed this before and it is such a relief (Eve)*. Another participant admitted *It has been quite a revelation for me that you can push away certain feelings (Colleen)*. One participant likened her previously unspoken emotions to the layers of an onion. Slicing through onion layers or “rings” can induce crying and for this participant the exposure of her “onion rings” also resulted in shedding tears.

There are these onion rings and I can't open them. You can't skin them open. There is no one to look at them. I don't howl very often. I didn't know I could bare my soul (Debbie).

The reluctance of the participants prior to this study, to discuss their innermost feelings about their partners' communication difficulties could be seen as a protection against admitting this aspect of the neurological condition on their lives. When the participants entered into self disclosure during the interviews they identified this as risk taking. One participant described this as a feeling of exposure and she identified that after exposure she would require assistance to recover from that exposure.

I would feel so exposed and I don't really know if I could share something like that. I don't know if I could open myself up to anyone else .Not necessarily share it but open myself up. Cause I still have to recover from it (Debbie).

In my role as a Parkinson's Nurse Specialist, and prior to this study, I had been aware of the stresses and frustration experienced by many partners or carers. However the extent of the reluctance of partners to disclose their innermost feelings resulting from changes in their husbands' communication had not been acknowledged or investigated. The perceived risk involved in self disclosure is associated with and due to the sharing of feelings and the vulnerability that can result from that sharing (Verderber & Verderber, 2001). A study into disclosure among patients in the palliative care setting revealed that patients were more likely to disclose physical concerns than psychosocial concerns and that more than 60% of concerns were withheld (Heaven and Maguire, 1998, p. 507). The disclosure of family members is not recorded.

The acknowledgement of emotions such as anger and frustration surfaced early in each of the interviews. As a consequence of the admission of these feelings came the resulting sadness and guilt which augmented the emotional turmoil. *I've just realized that I am very angry about [spouse] having Parkinson's disease and that makes me very sad (Debbie)*. Another participant identified her emotional response as one of frustration. *I feel terribly frustrated maybe because I like to talk a lot. I imagine it is frustrating for him too (Beth)*. For yet another participant in the study the

emotional response was anger. *I have become very angry with him and the disease and I pray that I will be forgiven for the anger (Eve).*

The physical and emotional energy required by the partners to participate in basic communication is described as being so great that at times the effort required could not be summoned. *Communication requires so much energy and I just don't have that energy (Eve).* One participant acknowledged that the effort required to communicate was not unilateral and this resulted in further feelings of guilt as she denied her partner his opportunity to dialogue. The inability to maintain the physical and emotional energy required to carry out communication also resulted in feelings of guilt which added to the existing turmoil of emotions such as anger and frustration.

Every time you want to communicate it's such an effort. Not just for me but for him as well. And that results in you having to push yourself to make an effort to talk because you know the person will want to but can't. Sometime I feel that I can't be bothered. I remember times when I said... "Just forget it", and you feel guilty afterwards (Colleen).

I get so angry trying to wait for him to say it that I could just about scream. I have to try to be patient and quite often I feel like saying ...If it's not important don't say it! You know you are closing off conversation because you get so frustrated (Amy).

At no time did the participants identify that the emotions of anger and frustration they were experiencing may be a natural response to their circumstances. This omission may be due, in part, to the widely held view that "carers" are ever smiling, good natured martyrs. These saint-like qualities are described by an unnamed person with Parkinson's disease (Anonymous, 1997).

This is where our wives can do wonders, thanks on the one hand to feminine tenacity, and on the other hand their intuitive sense of how to help us better to bear our lot, awakening natural, undreamt of vocations within us, whether in the field of the arts, sport, or other occupational therapies that may restore some of our former 'joie de vivre'Thanks to Parkinson's disease, our wives' self-abnegation, caring, patience and tenderness amount to one single word: love (p11).

This view supports the expectation that the female partner will cope with the changes brought about by the effects of the disease process. However if this is not the case the female partner may not openly express her true feelings. One effect of another's weakness, distress or disability is to act as a form of restraint on the expression of aggression or anger (Argyle, 1994, p. 8). This may explain why the participants had never previously expressed their anger or frustration. Lerner (1985, p.1) defines anger as a signal which may be related to a number of causes. These include a hurt, that rights are being violated, that our needs are not being met or that something is not right. The basis of her work is that women have

been long discouraged to admit anger. This would be especially valid for partners who are caring for or living with someone with a progressive neurological condition.

The participants in my study have revealed by their honesty that partners of people with communication difficulties arising from Parkinson's disease can and do experience emotions such as anger and frustration. These emotions subsequently led to the feelings of sadness and guilt which become enmeshed in Emotional Turmoil.

Confronting the Physical

The main theme of Emotional Turmoil is comprised of three sub themes identified from the interviews. Each participant identified that the physical manifestations of Parkinson's disease impacted on their relationship and this gave rise to an emotional response. This is identified as the sub theme, "confronting the physical." This sub theme is defined as acknowledging the physical changes wrought by Parkinson's disease. Dealing with the outward transformation of their partners was identified as a cause for emotional turmoil for the participants.

Handwriting was identified as being one aspect of communication where the obvious physical changes were evident and challenging. Handwriting is not a commonly acknowledged method of communication between partners, however difficulty in this area is described as having emotional consequences. For one participant the classic Parkinson's symptom of **micrographia** was an early precursor of the diagnosis. Even at that early stage the emotional response to the physical manifestation led to turmoil and feelings of anxiety.

The one that caused the trouble in the first place was the writing because [spouse] always thought that his writing could be understood and it took many years until he figured out that people couldn't understand it and he would have to stop writing or find new ways of doing it. Then when he first was diagnosed I was a student and he used to help me correct essays and he would write in the margins and he would sit beside me to explain what he had written and I couldn't read it and often he couldn't read it either. I went into a slight panic attack every time he tried to help me and I knew there was going to be a feeling of horror every time I had to go through that. (Amy)

In the experience of this participant there were expressions of relief from friends and co-workers when the diagnosis was made and the problem identified. *People at work said they were so relieved when they found out what was wrong as he didn't have to make people try and understand his writing (Amy).*

The problems involved with changes in handwriting evoked both practical and emotional responses from all participants. *I have signing powers now so he doesn't even have to write. So there's no problem. I don't mind too much about the handwriting. (Beth)* This would appear to be the simplest way to overcome the problem but for others the attempts to maintain independence resulted in additional emotional turmoil. *I find I write the cheques, I am taking over. (Debbie)* The personal implications of difficulty with writing were described by one participant with accompanying tears. *For my birthday the other day. It took him three days to write the card, because he shook so much. And that is sad. That really is sad. (Colleen)*

The physical changes also related to personal hygiene and this was interpreted by the participants as being related to non verbal communication. The participants identified that a lack of attention to personal grooming reflected a negative shift in the dynamics of their relationship and was identified as a sign that the partner did not make an effort.

Sometimes he gets jam all over his hands and that gets on the table and the cups. Everything. It's sticky and he gets food all over his face. He doesn't clean up. Do I say to myself, well he has got Parkinson's? (Debbie)

For the partners interviewed some of the physical changes related to personal hygiene were so insidious and subtle that they required clarification during the interview as to which were related to Parkinson's disease or which were due to apathy. *It's not socially acceptable. Is that Parkinson's or is that slack? (Debbie)*. Another participant identified the changes in attention to detail in personal grooming. *He was always fastidious before but now he gets around in the oldest jeans and grubbier shirt. Now I have to tell him to have a shower. Maybe that's a taste of what's to come (Beth).*

With the ongoing deterioration, related to the disease process, leading to obvious physical changes the participants described their responses at a more personal level. The physical intimacy of marriage did not escape the impact of the observed changes. The emotional responses resulting from these physical changes were expressed with great honesty and grief.

As the disease progresses and his physical condition gets worse, I feel a form of, and this dead honest, a sort of revulsion. And of course this is going to carry over to the bedroom and everything. He's not the man I married you know, so there is a huge amount of sorrow (Eve).

The transition from the role of sexual partner to a partner having to carry out care related to bodily functions added to the challenge of "confronting the physical." For one participant, while the original affection in the relationship remained it was difficult to feel a reciprocal desire for intimacy when she had taken over core activities such as management of constipation. This again resulted in a clash of emotions.

When you start dealing with someone who has constipation and you are giving someone enemas it is very difficult to expect you falling into their arms and making love as well. You know it just doesn't happen. There is a decline in all those sorts of physical relationships that used to mean so much. I guess I feel guilty about it but that's the way it is (Amy).

The impact of Parkinson's disease on non verbal communication between couples in a longstanding relationship was addressed by the participants as being the cause of sadness. The casual reaching out to touch and acknowledge, in an intimate manner, the physical presence of a partner had been stolen by the nature of the progressive neurological disease that is Parkinson's disease. *It affects the whole body. Even to touching (Eve).* Yet another participant identified that this element of communication was being adversely affected.

He's not communicating, he's more in himself. He's not reaching out to pinch my backside any more or give me a little pat on it as he passes, or a cuddle (Debbie).

Floyd and Morman (1998, p.157) examine the importance of affectionate communication in developing and maintaining intimate relationships. Affectionate communication is described as non verbal behavior such as holding hands, hugging or kissing. It is clear from the data available from the participants in my study that they felt that this aspect of their communication with their partners had been changed by the impact of Parkinson's disease.

The impact of illness and the subsequent shift in the purpose of touch between partners has been addressed in palliative care. White (2003) outlines the possible conflict when partners are involved in the delivery of personal care. The example drawn from an interview with a woman with a terminal illness describes the reluctance of the person with the condition to substitute her partner's prior sexual touch for clinical assistance. 'He used to undress me in a sexual way; now it is like I am a child. I hate every minute of it' (p. 255). This observation from a patient concurs with the emotional confusion verbalized by Amy.

Physical intimacy and Parkinson's disease is a common topic of discussion (Blake-Krebs & Herman, 2001; Lieberman, 2002; Oxtoby, Williams, & Iansek, 2002). These discussions commonly address the physical manifestations of impotence or the less openly discussed issue of hyper-libidity. Bronner (2002) describes a study of a short term intervention programme for both partners. The therapy offered a sex counseling service to address sexual dysfunction. While the goal of the therapy described was to add to sexual activity and pleasure for the person with Parkinson's disease the author acknowledges that the desire felt by the partner of the person with Parkinson's disease can be affected by similar influences such as those described by the participants in my study. These are listed as

drooling, sloppy dressing and postural changes (Bronner, 2002, p. 9) rather than the shift in physical contact from a sexual nature to a care-giving role.

Literature written by partners and pertaining to relationships affected by Parkinson's disease do not address the issue of sexual desire or intimacy (Carlton, 1998; Heafey, 2001; Kidd, 1999) This can be attributed to the previously discussed risk perceived in self disclosure especially at this intimate level. This deficit augments the depth of self disclosure in my study. The participants were fluent in the descriptions of their responses and the turmoil evoked by these feelings. Their openness and honesty must be acknowledged and warrants further exploration.

The Condition Always Wins

The second sub theme identified under the main theme of Emotional Turmoil is “the condition always wins.” In addition to the physical challenges facing the participants, they identified that the disease process in their partners had resulted in an inequity in their relationships which had not previously been encountered. The analysis of the data derived from the interviews led to the identification of the second sub theme, a perception that “the condition always wins.” This is defined by the participants as a loss of control at times of discussion or disagreement. It is at times of conflict and stress within the relationship that the disease is seen as a winner. *Mr. Parkinson's always wins. (Beth)*

The personalization of Parkinson's disease as a third person in the relationship at times of discord, argument and stress confirms the far reaching impact of this neurological condition. The commonality of the description of the disease as a victor was an unexpected phenomenon. Each participant personalized the condition as being a third party in arguments or interactions. This resulted in an emotional turmoil that was both challenging and confusing. The perception of Parkinson's disease as a third party in arguments and discord was related to the physical manifestations of the condition rather than the acknowledgement that the person had a neurological condition. The effect of stress or excitement in Parkinson's disease is to exacerbate the visual symptoms such as tremor. *I can't argue with [spouse] because he shakes so much. (Eve)*

The acknowledgement that discussions and disagreements are a normal component of communication within a relationship was expressed. The participants clearly identified that this was an area which is denied to them as partners living with someone with

communication difficulties. The participants realized that this experience was bipartisan but the personal frustration experienced by the participants was stronger than their understanding of the loss experienced by the person with Parkinson's disease in regard to this aspect of communication.

We can be loving and all those other things that are part of a marriage but we cannot have a decent argument. A decent discussion on anything I feel strongly about. That he feels strongly about. I will back out because of how it affects his Parkinson's, and it's been like that for about five years now. (Debbie)

Carrying on from the previous quotation this participant expressed her perception that there was no hope of winning in a situation where the effects of confrontation impacted on the symptoms of the condition.

That's what's wrong with Parkinson's. I'm always the loser. I'm always the loser because [spouse] and Parkinson's wins, although he doesn't know he wins, because I have to shut up because he gets so upset and shakes so much. It will take him days to recover from me challenging him and saying that I don't agree with him. (Debbie)

For another participant, the frustration involved in being denied discussions or arguments is attributed to the use of a machine for communication. The spontaneity of communication is compromised by the mechanical strategies necessary to maintain basic verbal communication. For this participant, whose husband is unable to speak, the use of a **Lightwriter** is not the ideal way for a husband and wife to communicate in times of disagreement.

We really have no conversation at all. It's very, very minimal and quite often when he uses the machine, if it's an argument, like if we are having a disagreement about something and he wants to follow up on it he will say it on the machine. Have you ever tried having an argument with someone with lots of pauses. You can't yell and shout and scream at each other and go back and forward with each other when you have to wait for someone to type it on a machine. It sort of takes the top of it. You know it's not much of an argument. (Amy)

For another participant, who for a short period utilized an alphabet board as a tool to overcome a festinating speech pattern, the resulting frustration was evident in her assessment of her spouse's capabilities. *It was like extracting information from someone who wasn't really capable. (Eve)*

The withdrawal from arguments and confrontations is described as being both the inability to speak and the impact of stress on symptoms. *It's just physically impossible for [spouse] to argue with me. (Eve)* For yet another participant the disease process transformed her husband from his previously argumentative personality to a more placid state. This denied her the opportunity to continue the previously recognized pattern of discussion and negotiation.

However, for *Colleen*, the change in her partner's personality was identified as a positive outcome in spite of the shift from previous methods of communication.

Through his Parkinson's he did mellow a lot because he had been an argumentative person. When he got Parkinson's he did mellow to the point where he sometimes surprises me at how he reacts to things that I knew before would have made him angry. (Colleen)

The inability to have an argument within a marriage or partnership may lead to feelings of frustration as described by the participants. *If you don't have a proper argument then you don't have resolution. A lot of things go unresolved. (Amy)* Yet another participant confirmed these feelings of frustration as being due to a lack of closure. The admission that this deficit is an area which would require personal adjustment and acceptance was acknowledged.

There's no closure. It's something that if you could have closure then you could at least put them to one side and get on with the next phase of life or your daily things, but there isn't. I think the carer has to deal with non closure. (Beth)

The inability to have an argument and the frustration associated with these changes in interaction led to one participant introducing a strategy aimed at improving the volume and strength of her spouse's voice. This is described as evoking emotions such as anger. The response was positive in that it temporarily raised the volume of the voice.

It used to be that I could make [spouse] angry. When he was having trouble talking, he could actually talk louder you know. I used to try to make him physically angry. Get angry I'd say. And then he would try to talk. (Amy)

While this strategy was introduced at a time when there was no formal physiological basis for its effectiveness a recent American study investigated the impact of emotion in inducing verbal **kinesia paradoxia**. Crucianet al. (2001) recognizing that patients with Parkinson's disease demonstrate impairment in facial expression, volume, tone and emotional expression measured the impact of induced emotion on these characteristics of Parkinson's disease in 13 subjects. The results were compared to a control group with the outcome demonstrating that high arousal emotions, such as anger, stimulated verbal output in the Parkinson's disease subjects (p. 159-165). This confirmed the previously unfounded experience of the participant in my study.

The longevity of the partnerships of the participants in my study adds to the consequence of the lack of discussion and argument. As couples in partnership grow to know each other over extended periods of time they encounter many subjects to explore, discuss and argue, and they have to work through these disagreements (Argyle, 1994, p.148).

The inequity in communication and the perceived victory of Parkinson's disease in the relationships as described by the participants is a potential for dissatisfaction within the marriage. The exchange theory originating from Thibaut and Kelly (1986) explores the balance between rewards and costs in interactive situations. This theory is expanded by Verderber and Verderber (2001, p. 81) into relationship issues when a person whose "net rewards fall below a certain level that person will come to view the relationship as unsatisfactory or unpleasant." This confirms the lived experience of the participants interviewed in my study.

The interviews in this study revealed that when communication difficulties impact on a relationship the potential exists for the partner with intact communication skills to assume the dominant role in the partnership. *I'm taking away his manhood. (Debbie)* This is a phenomenon I had previously observed in clinical practice but the realization that the assuming of the dominant role by the female partners was unwelcome had not been explored. However the participants in my study described their reluctance to assume the dominant role and all identified the change in dynamics within the relationship. *I would rather he had the feeling that he is the boss. (Eve)*

The assumption of the dominant role leads to the gradual transference of the previously male managed aspects of daily and married life. *It's very easy for me to overrule anything he wants. (Amy)* This was commonly acknowledged as being a result of the communication changes and difficulties. The change in role status results in added emotional confusion. For one participant this was experienced as loneliness and was likened to facing the world alone. *It's like being a single parent family. You have to make all the arrangements. (Eve)* This experience of being alone within the partnership was common to the participants and was related to similar scenarios.

I'm taking over in many things that I wouldn't have done like having the electrician putting a light in the caravan. Once upon a time I wouldn't have had anything to do with that. But I have done it all. (Colleen)

The social interaction between life partners is defined as a horizontal or equal relationship. A deviation from horizontal interaction for any reason will lead to an alteration in role status (Fuller & Schaller-Ayers, 1990, p.387). Equality in communication is usually shown by the exclusion of any words or non verbal signs which may indicate superiority (Verderber & Verderber, 2001, p. 94). The authors go on to state that the opposite of treating others as equals is to control them. Every relationship is unique and the partners have arrived at their own determination of role status.

If an outside influence, such as Parkinson's disease, interferes with that role status the result can be emotions such as resentment and confusion. The concept of collaboration between partners as a method of coping with the impact of chronic illness on a relationship was explored by Corbin and Strauss (1984, p. 109). A major recommendation by these authors in order to achieve a mutually acceptable outcome was for the partners to communicate:

The third step involves assisting the couple to resolve the problem through talk, talking about it, talking it over, and talking it through. It is through talk that they can come to develop shared trajectory projections, goals and action schemes. It is through talk that they can come to resolve some of their differences over lost hopes and dreams for the future and to develop new ones that coincide with the limitations imposed by the illness. (p. 114).

Parkinson's disease and the impact on all aspects of communication will render this advice impractical for both partners affected by communication difficulties. It is therefore imperative that the body of knowledge be expanded by further study and exploration of the experiences of this unique group of people affected by a variety of communication changes and difficulties.

The result of my study was to identify the emotions common to the partners of people with Parkinson's disease affected by communication changes. These emotions are compounded by the perception that "the condition always wins" and the fact that the partner has to confront the physical changes obvious in their husband. These two sub - themes combine to be in part a cause of the emergence of the third sub theme, "social isolation".

Social Isolation

The participants provided descriptions of withdrawal from social interactions which pervaded all relationships. The emergent sub theme "social isolation" explores these acts of withdrawal and the emotional responses to the isolation. Social isolation is defined as lack of contact from within the partnership and from others. The participants identified that the social isolation was initiated by the person with Parkinson's disease, the family and friends in addition to their own withdrawal which resulted from the communication changes and difficulties. It is the emotional responses resulting in turmoil which are the common threads between the sub- themes, "confronting the physical", "loss of control" and "social isolation".

The initial isolation was perceived by the partners to be a withdrawal by the person with Parkinson's disease. The withdrawal described is not solely a physical withdrawal but also an emotional isolation. The person with the condition will be physically present but the partner is aware of a withdrawal of the sense of the person. It was acknowledged that this may not be a conscious decision to withdraw but is a result of the impact of communication changes due to Parkinson's disease. *My husband, as a person, has just retreated.*

(Beth) This concept of withdrawal was expressed by another participant as: *I think he is isolating himself but he won't know that he is doing it. Because if he knew he would be very sad and would try to do something about it. (Debbie)*

While inaccuracies in perception are common in communication generally (Verderber & Verderber, 2001, p. 63) the degree of closeness previously experienced and length of the relationship described adds to the clarity and veracity of the insight described by the participants. The observations of the participants in my study are verified by others in a similar situation. For a husband who described his wife's journey with Parkinson's disease in a journal, this withdrawal or isolation is described as a "slipping away or a moon fading too soon" (Hallum, 1984 p. 123).

Pursuant to the social isolation by the person with Parkinson's disease the partners describe their emotional responses. The description of grief as a response is likened to that experienced at a time of death or the period of grief prior to the eventual death of a partner. *I seem to be losing him fast. (Eve)* The realization that the partnership is drawing towards a natural closure is common to other participants. *He's dying and each day he dies a little bit more. (Debbie)*

For several participants the impact of Parkinson's disease led to a complete inability by their partners to participate in verbal communication. This lack of reciprocity is described as a great loss in the relationships. *You don't get any feedback in anything. (Eve)* This results in added stresses for the partner from both the practical aspect and the social isolation resulting from living in a silent home. Amy's description of her life as a guessing game has been discussed in a previous chapter. However she acknowledged with a sad smile that this was *no game. (Amy)* She introduced a strategy aimed at maintaining her communication skills in order to provide some semblance of communication within the home. She drew on the memory of her mother playing Scrabble one hand against the other and likens this to her strategy of speaking to herself and then providing a spoken response to her own

comments. This substitution mechanism replaces normal communication within the home until the presence of guests who can speak bring the participant back to the reality of interactive communication. However the unfamiliarity of response can be challenging. *I find when other people are in the house and they give me feedback it is really strange because I have got used to such a silent world. (Amy)*

As the disease progresses and the strategies previously used prove no longer helpful the partners change the focus of strategies from those addressing their partners' communication needs to ameliorating their personal situation. The participants describe several ways of coping with the social isolation. For some this takes the form of spending time on the telephone talking to girlfriends or having time away with family. The participants verbalized that spending time with others was a negative reflection on the partnership. They did not see this as a positive coping skill but confirmation of the negative nature of their emotional response was petitioned. *So I'm not facing it? So that's me isolating more? (Debbie)* Another participant stated... *It hurts me because I'm not including him in conversations I have with people. (Amy)* The time and affection given to a family pet was evaluated as a negative response because it was time and energy denied to the person with the condition. However the feedback and companionship received from the dog was acknowledged as a positive.

I give the dog more attention and love than I give [spouse]. I feel really bad about that but it's because I get feedback from the dog you know. She's such a comfort to us both because she accepts him. She doesn't know that he can't talk and she accepts him anyway. But she is someone that I can talk to and have a lot of fun with. That's where I get a lot of fun in my life, through the dog. (Amy)

The widespread source of social isolation was seen to include family and friends. The gradual realization that family and friends were withdrawing is described without rancor or malice. It is attributed to a lack of response from the person with Parkinson's disease. *They have tended to pull away because people need someone to respond to you know. (Beth)*

One participant described the necessity to remind their children to include her partner in conversations. *He is often ignored. I have to speak to the children and tell them to talk to their father. It is hard for them to sit with him because they don't get a response (Colleen).* The "sharing of the disease" results in the isolation of both partner and person with the condition. This isolation is both a physical withdrawal resulting from a lack of response from the person with the condition but also the lack of knowledge or understanding on the part of family or friends of the emotional isolation experienced by the partners. *I have retreated a bit. People need somebody to respond to you know. (Beth)* The lack of understanding is highlighted by another participant. *The worse thing is that I feel quite alone and people don't understand. No one seems to accept what it is like. (Colleen)* The energy required to communicate

is seen as too difficult to summon and this in turn leads to a decline in communication for all concerned. *Communication is such an effort, for him and for me. (Eve)*

The effect of a lack of response or interaction is described by the wife of a person with Parkinson's disease. Greene (2000, p. 40) likens living with someone who does not respond spontaneously to reading a book about which the cover tells you nothing. She accurately describes the emotional reactions of people outside the partnership to the closed book. These reactions include the person with Parkinson's disease being ignored which may result in antagonism, an assumption that the person with Parkinson's disease is dull and boring which results in expressions of negativity to the person. The response described as being most common is to walk away. This confirms the potential for social isolation resulting from the lack of communication, both verbal and non verbal, as expressed by the participants in my study.

For one participant the withdrawal of her main social support was due to the death of her friend. This loss was exclaimed with a mixture of anger, regret and humour. As yet there has not been a replacement for the lost friend. *I feel there is no-one out there to listen to me. I had a best friend and she was my soul mate and she died. Bugger her!!! (Debbie)*

Argyle (1994, p. 162) describes the skills necessary for successful management of all relationships, both espousal and non espousal. These include non verbal communication such as smiling, conversational skills and assertiveness. These nominated skills are those which are often primarily affected by Parkinson's disease and therefore will by their absence affect all social interaction. The importance of a strong social support is associated with hope in times of illness (Miller & Powers, 1998; Miller, 1992; Rustoen & Hanestad, 1998). It can be surmised therefore that the withdrawal of social support, or social isolation, will be a component of emotional turmoil brought about by the disease process.

Conclusion

This chapter has explored the emotional responses of the participants to the communication difficulties demonstrated by their partners with Parkinson's disease. These responses include anger, guilt, frustration, sadness and loneliness. The participants recognized that the disease process is the culprit and for the majority the disease was personalized as a third person in the marriage. This third person was seen to be the victor

in times of conflict and this added to the frustration felt. The presence of “Mr. Parkinson” within the relationship and his overwhelming control led to feelings of helplessness and inequity which compounded the existing challenges to communication within the relationship. The impact of Parkinson's disease led to communication changes which in turn led to a withdrawal by the person with the condition, the partnership affected by the condition of Parkinson's disease and also their friends and family. The Emotional Turmoil identified by the participants has been disclosed and explored. The impact of the physical manifestations of the disease has been highlighted as an issue for the partners of people with Parkinson's disease. These emotional and physical changes have been proven to lead to Social Isolation for the partner of a person with Parkinson's disease who demonstrates communication changes.

CHAPTER SIX

Ways of Coping

Introduction

The final theme Ways of Coping is defined as strategies identified by the participants as necessary to deal with the impact of communication changes on the partnership. The strategies introduced varied according to the needs of the individual but the necessity for their existence was common to each of the partners interviewed. Within the major theme were the three sub themes of: “know the beast,” “share the burden”, and “the road ahead”. The major theme and the sub themes will be discussed in relation to pertinent literature. Outlined below in Figure 4 is the third major theme and associated sub-themes.

Theme	Definition of Theme	Sub-themes	Definitions of Sub-themes.
Ways of Coping.	Skills and Mechanisms used in dealing with the impact of Communication Changes	<ul style="list-style-type: none">• Share the Burden• Know the Beast• The Road Ahead.	<ul style="list-style-type: none">• Seeking out company other than the person with Parkinson's disease• Seeking out Information• Preparing for the future

Figure 6:1 Ways of Coping

Ways of Coping

Uncertainty is endemic to the human condition (Pinder, 1990, p. 77). The participants in my study identified that in order to deal with the emotional and physical impact of Parkinson's disease they utilised both accepted and unusual ways of coping with uncertainty. The acknowledgement that the maintenance of hope and flexibility was vital was verbalised by some participants as both an early and ongoing method of coping with a future which is uncertain. *As one dream changes you make another dream. You always have to have a dream. You need a dream. If it doesn't come to fruition you have to change it. But you still have to have a dream (Debbie).*

For the participant whose husband had died prior to the interview she was able to analyse the value of the hope given to her and her husband by ongoing speech therapy following a **pallidotomy** which resulted in **aphasia**.

We were still hopeful that it was a temporary thing. We kept thinking that it was helping and that kept us going and in hindsight you see now that it never really did help but it gave us hope and that was probably important (Colleen).

For another participant whose husband is unable to speak or write because of the natural progression of Parkinson's disease, hope was not acknowledged and when she discussed meeting with other partners of newly diagnosed people her response indicated that this would not be an option as hope was not a coping mechanism. Nor was it a memory of the hindsight of her experience. The relief she initially felt at the time of her husband's diagnosis has been replaced with hopelessness and horror.

If someone had told me that in ten years down the road [spouse] wouldn't be able to talk or write, I would have been shocked and horrified and terrified. So these things dawn on you. They dawn on you slowly. So don't let me talk to any newly diagnosed people (Amy).

Another participant verbalised her overall hope that a cure for the disease would be found and that would be the solution to her situation. *Maybe a cure will be discovered soon and it will fade away (Eve).*

The ability of humans to adapt to changes in health and life patterns is a characteristic of the resilience of human nature. The concepts of enduring, uncertainty, suffering and hope are linked by qualitative analysis by Morse and Penrod (1999). Enduring is described as the way a person "gets through" a situation that is extraordinary and requires them to put their emotions on hold. This confirms enduring as a present time

orientated state of being (Morse & Penrod, 1999, p.150). This can be identified in *Amy's* description of her situation where she denies any hope in her experience. In contrast, hope is an expectation and the protagonists in the situation become future orientated (Morse & Penrod, 1999, p.151). The experiences of *Colleen*, *Debbie* and *Eve* reveal that the concept of hope constitutes a part of their coping strategies.

One participant had watched her mother affected by Parkinson's disease and was therefore in part prepared for the transformation of her husband following his diagnosis. She became proactive in the progression of his disease and utilised a diary to monitor and observe the changes. She is aware that, in addition to compiling a diary of the disease progression she, in the future, will have a personal journal describing the husband she had before *he retreats (Beth)*. It can be conjectured that this journal will be therapeutic for her when she reflects on it and her husband's past life.

Maybe just by getting it down on the computer just for myself. It may never be used for a book. Just for myself, maybe it will be a kind of journal because you know one does forget. You notice something one day and a week down the road something else goes and you totally forget it (Beth).

The purpose of a diary for this participant was not simply for self reflection but for comparison and confirmation of symptoms with others. This was particularly important for this partner as she lived overseas in an isolated area where there was no access to a Parkinson's support group. *Maybe I'll pick up a bit of correspondence about Parkinson's and compare notes and think, 'Ah someone else has got the same thing, and then I know it is related to Parkinson's disease (Beth).*

It became clear from the analysis of the interview material that the participants used practical strategies in order to cope with the various stages of the journey with their partner and Parkinson's disease. In the earlier days, when the impact on communication was less obvious and problematic, less effort was required to address the problems. For one participant these included teaching the person with Parkinson's disease to write upside down and backwards, using a communication aid, such as a cue card or, as discussed in the previous chapter, inciting an emotion such as anger. These strategies described by one participant were successful for periods of time and the result was worth the considerable effort required from both partners. *There is a certain amount of delight in being able to find a solution to a problem. When you find solutions that is fantastic! (Amy).*

While the participants recognised that their situation was potentially isolating they described several ways of coping which involved looking beyond the partnership for diversion and support. The methods of support and diversion varied according to the interests and personality of the participants. For the majority of the partners interviewed the support was not from close family but from interests such as hobbies and pets. The value of maintaining outside interests was acknowledged as vital. Physical activity was identified as a great method of coping with the loneliness and isolation brought about by the communication changes related to Parkinson's disease. However the isolation associated with some of the activities was acknowledged by one participant.

I have to make a very real effort to go swimming because that is something I need, and it is a really good space for me. It is everything, apart from the fact that I don't talk to anyone when I do it (laughter). It is a good headspace for me to be in and it is good for caring for your own body too (Eve).

Physical activity was a release for other participants and this involved interacting with other people on a casual basis. The social interaction with others was not sought but was a natural aspect of walking with a dog. However it was identified as a need and a way of addressing that need.

I was thinking the other day how much I do appreciate the feedback from other people and thinking about my daily interactions and when I go walking the dog I know quite a few people on one side of the street and I stop and talk to them and so my day starts off with interactions, with interacting with other dog owners and other dogs. That's very good. That supplies the needs, you know (Amy).

The future impact of the progression of the disease process was acknowledged as a possible obstacle to this coping strategy and the implications of this were dreaded. This participant was well aware of the dangers of carer isolation and was able to project to that time. Although she was already in an isolated situation within the partnership as her husband is unable to communicate verbally she realised that the future was predictable.

When I can't leave [spouse] it is going to become difficult. If I can't leave him to go for walks with the dog, then I won't get that interaction so all the classic things about the carer getting isolated will ultimately happen to me, I suppose (Amy).

The companionship and responses of the dog were of immense comfort to this participant and were vital to her coping with the situation. However even this way of coping gave way to an emotional response. *She (the dog) is just so precious and she cuddles with you. She is someone that I talk to and play with and have a lot of fun with so that is where I get a lot of the fun in my life, through the dog (Amy).*

The companionship and coping strategy made available by the pet was also a way of sharing some level of interaction with her husband and this assisted both parties to cope with the situation. The ability to roll on the floor with the dog and the dog's ability to communicate with the person with Parkinson's disease acted as a bridge between the couple and was regarded as more therapeutic than a counsellor.

We get down on the floor together and roll around and do typical doggy things together. So we find that the few times we laugh together is when we are laughing at the dog. So that is really good. It is much more natural and relaxed than having a third person to talk to. This is something you can enjoy without language (Amy).

The experiences of this participant in owning and having proximity to a pet are well researched phenomena (Knapp, 1998; Lee, 1981; Muschel, 1985). Pet therapy can help the owner develop an outward focus. This may be because animals have a way of unconditional acceptance. This acceptance is non judgemental and unaffected by the impact of disease such as is described by Amy. Beck and Katcher, (1996) document Amy's understanding of the use of her dog in lieu of a therapist. They describe the relationship between pets and people as "therapeutic intimacy" (p.92).

Each participant identified different foci for their attention in order to cope with the situation of living with a partner whose communication was affected by Parkinson's disease. For one participant this is her craft work. However the attention and time she gave to this hobby or way of coping met with some objection from her partner, the person with Parkinson's disease. This objection led to great grief and long lasting emotional turmoil.

I was making books for our grandchildren. They go from A to Z and each one is embroidered and appliquéd. It took forever to make them. But it was then that [spouse] was diagnosed with depression. He blamed my books for his depression and my stomach is still churning over that. He told the counsellor that that was why he 's depressed because I had spent so much time making those books. (Debbie).

The value of maintaining one's self image and femininity by strategies such as visits to the hairdresser or beautician were described by one participant as a strategy or coping with the impact of her situation.

They always say ladies look after yourselves but I must admit I never did before. But now I have made time. I have two lovely hairdressers, either one does my hair and I'll go to them and say, 'I need some tender loving care' and they will say, 'sit down,' and half an hour later I go out of there feeling great (Beth).

The strategies or ways of coping described by the participants in my study closely mimic the checklist for carers outlined by a United Kingdom Parkinson's newsletter. This list

included doing something for oneself every day, physical exercise on a weekly basis, maintaining time for hobbies and talking to friends (The Parkinson, 2001, p. 19). In addition, this publication advised the carers of people with Parkinson's to talk to other people in similar circumstances. Mc Gonigle (1999) describes the introduction of hobbies, crafts, travel and physical contact with grandchildren as 'sublimation'. Tactile activities in particular are described as being of value as a substitute for sexual contact. The sub conscious introduction of such activities by the participants in my study is confirmed by literature as being therapeutic for anyone who finds themselves in a similar situation.

The major theme Ways of Coping was identified from the interviews with the partners of people with Parkinson's disease who demonstrate communication changes. The isolation and emotional turmoil arising from their situation led the participants to explore assistive strategies. These mechanisms for coping were as individualised as the participants interviewed but the need for them and the honesty in describing them was universal to each spouse interviewed. The theme Ways of Coping was then explored through the identification of sub themes. The first sub theme within the context of Ways of Coping will be discussed under the title of "sharing the burden".

Sharing the Burden

Data analysis resulted in the identification of the sub theme "sharing the burden". This sub theme is defined as seeking out company other than the person with Parkinson's disease. One participant described this as a necessity rather than a choice: *I need somebody to share with me. Listen to me. (Debbie).*

Both the benefits and obstacles arising from discussing their situation and responses to that situation in the format of the interviews necessary for this study have already been described and acknowledged in the discussion on Emotional Turmoil. However in addition to those mixed initial responses the participants described their need to align themselves with others. *The most important thing is to know that you are not alone out there (Eve).*

For one participant this involved travel to Australia on holiday where she could meet with a support group for people with Parkinson's disease and talk to others who were partners of people with Parkinson's. The relief obtained from meeting with others in a

similar situation and subsequent lessening of the isolation was also acknowledged by this participant. *When you see other people doing it you realise, we are all in this together. They are coping. You can cope (Beth).* This opportunity was regarded as an added benefit of the holiday. In addition learning by observation of others was reported as beneficial.

Like I went to a support group and there were some lovely folk there. I noticed the wife of one elderly gentleman, he had a bad tremor. His little alarm clock went off and she prompted him with his pills. She didn't help him. She oversaw him taking them. I knew then that I had to do that as well (Beth).

Another participant identified the value of "sharing the burden" as a preventative measure against losing her own communication skills. She recognised that the potential lack of opportunity to interact with others could impair her own communication skills.

You begin to doubt your own ability to converse with people. If you spend too much time with the person with Parkinson's disease you forget how to relate to other people and it comes as a shock to find that you can't talk any more. So it is important to go out and talk to other people (Amy).

This participant however did not recount a need to attend a support group. Her sharing of the burden was described as being spontaneous rather than a conscious seeking out of homogenous company. *You find these openings in life and you find solutions to that silence. You don't really go out and say 'I'm going to find someone to talk to today' (Amy).*

The willingness to share was dependent on the ability to open up to others and this can again be linked to the fear of disclosure discussed in Chapter Five. Therefore it is understandable that all each of the participants described various methods of sharing the burden. For one, while the reluctance to share was described, she identified that it may be necessary to adjust to the concept of sharing.

I am not a great one for coffee with the girls, even though I love it when I do it. I am just not a great one to do that. But I am going to have to learn some new techniques to help me share (Eve).

For another participant the ability to confide in her sister who had previously been a sounding board was now compromised by a change in her sister's situation. The participant felt that her sister was becoming egocentric. This block to communication denied the participant the opportunity to have her emotional needs met. The description of this change in communication dynamics is a lesson in the art of listening and support. This participant identified that as a partner of someone with Parkinson's disease who is affected by communication difficulties she had a need to be heard in order to share the burden.

My sister is becoming very anxious too. She is developing her own medical problems and is becoming very self centred. Now she doesn't say, 'I hear what you are saying', she will say 'Oh yes, that happens to me too blah, blah, blah. I need her to listen to me. And I don't think I am being unrealistic' (Debbie).

In spite of this block to sharing, Debbie was appreciative of the availability of both a daughter in law and daughter who were intuitive and able to pick up the subtle signs of stress or turmoil rather than expect the participant to ask for support. *She (daughter in law) can pick it up in my voice, and my daughter will say, 'Where has your voice gone? What is the problem?' (Debbie).*

For the participant whose partner had died prior to the study the concept of sharing the burden was an important part of her coping with the isolation in the months spent looking after her husband at home. She recognised the probable risk of being *isolated in your situation* and had addressed this by reaching out to family and friends. The continuing importance of sharing the burden following the death of her husband sharing was acknowledged as of benefit.

I didn't withdraw myself. If you are fairly isolated in your own situation then it is definitely very important that you keep ringing people up and keep talking to people, even if you can't leave the house. Doing this has probably been and still is an advantage (Colleen).

There is much literature addressing the role of the unpaid caregiver. (Hayes, 1999; Holicky, 1996; Jones, 1994). The potential for isolation associated with the role of a carer is described by a Suzanne Mintz, a wife of a person with Parkinson's disease, as part of the common bond of care giving. In a South African Parkinson's Newsletter (2000 p. 2) she is cited as identifying the sense of isolation as being related to living outside the norm because the physical acts of providing care, such as dressing, feeding and toileting. However the need to "share the burden" and verbalise with others was not addressed in this publication. A recent Australian study comparing the needs of 55 carers of people with Multiple Sclerosis in Australia and United States of America identified that the majority of carers were married to the person receiving care. The study revealed that 56% of those surveyed had visited their family doctor in order to discuss their feelings and thereby reduce their stress. (Wollin and Sato, 2001, p.22). The qualitative arm of study on the caregiver burden in Multiple Sclerosis went on to report that the most common recommendation to be offered by the carers was "get support" (Wollin & Sato, 2001, p. 23). This confirms the identification of the first sub theme "sharing the burden" by the participants in my study on the lived experience of partners caring for people with Parkinson's disease who demonstrate communication difficulties or changes.

Knowing the Beast

The concept of “knowing the beast” was identified as the second sub theme within the theme Ways of Coping. The personalization of Parkinson's disease as both an intruder and a beast came from two participants. *Mr. Parkinson. That third person who is getting bigger and bigger (Debbie)*. The participant who lives overseas in a country where confronting wild life may be a daily threat described the disease as: *This disease is like a wild animal that we can't control (Beth)*. It was on this exemplar that the title for the sub theme was built. Knowing the beast is defined as seeking out information.

Data analysis highlighted the recognition that an understanding of the disease process of Parkinson's disease was necessary to assist the partners in adapting to the communication changes demonstrated by their spouses. The availability of education for partners was recognised as a need, but for one participant it was clear that this need must be balanced with normality in day to day life. For this reason she encourages others in similar situations to temper their search for knowledge and a cure with moderation. *I know now that it is important not to have an illness centred life (Eve)*.

The need to seek out information was described by the participants as being self initiated. The fact that, at the time of diagnosis, they were unable to verbalise their needs was explained. *Suddenly [spouse] has got Parkinson's disease and what is that? It's an old man with a shuffle. That was all I knew about it (Eve)*. The information was not made readily available to them on diagnosis. Each participant described their search and recounted their frustration that the information was not readily available. *I needed someone to answer the questions I didn't know to ask (Debbie)*. For this participant the quest for information involved a search and tenacity not commonly described.

[Spouse] was diagnosed on a Monday. On Wednesday I was coming home from work and I caught the tail end of Verity James {local radio announcer} talking to a doctor on the ABC about Parkinson's disease. I only caught the tail end but it gave me hope. I rang the ABC when I got home and said, 'Look, my husband has just been diagnosed with Parkinson's disease. I would really like to hear that programme. They arranged for me to go in the next day. I took the day off work. I went in. They set me up in a studio. They played the tape for me and without having to they made a copy of that tape and gave me all the information they had. And that was the first thing that gave us hope (Debbie).

For Colleen whose late husband experienced communication changes suddenly due to surgery for Parkinson's disease the experience of lack of information was similar. The impact of the lack of information at the time of the surgery was described as *really difficult for us*. The services offered as follow up were valuable and appreciated but the experience of this participant was that an explanation at the time would have assisted their coping.

During surgery for Parkinson's disease [spouse] had a CVA which was never discussed with us, which was really difficult for us because we wanted to know why his speech was suddenly affected. We were told there was a bit of swelling of the brain and that it would subside as time goes on. However it didn't. I would have preferred it if we had been told by the doctor that did the operation. They should have been honest with us (Colleen).

For the participant from overseas her experience on her husband's diagnosis was similar. *It's only when a person gets Parkinson's disease that you go, as in my case, to the library and try to figure it all out. We are not aware. We are actually very stupid (Beth)*. In spite of her late mother having suffered from Parkinson's disease the lack of knowledge and need for education was strong. This search for information was evident in her tenacity to seek out information while in Australia on holiday. The rationale for seeking knowledge is described as equipping the partner for the unknown future.

If you are aware of the changes you can make allowances for your husband. I think you should have the ammunition available to face the beast further down the road. (Beth).

The reported lack of information available to patients and their partners on diagnosis was a commonly described scenario. *The specialist who diagnosed [spouse] gave us a book and said, 'Come back in three months' (Eve)*. The observation of the participants that they were denied appropriate information and not equipped with knowledge at the time of diagnosis is frequently heard in clinical practice. However the decision by the diagnosing physician on the extent of information to give at the time of diagnosis remains an ethical dilemma. An oversupply of information can be distressing for some patients but a paucity of detail is, as recounted in my study, long remembered. Clinical communication is complex and finely balanced with content requiring adjustment in relation to contextual and personal variables (Komesaroff, 2003, p. 44).

Pinder (1990) in a British qualitative study, specific to Parkinson's disease, classified patients and their partners according to their requirements for information on diagnosis. The data was obtained by in depth interviews with 15 people with Parkinson's disease and 19 General Practitioners and led to three classifications. These were titled: Seekers of

Knowledge, who expected and demanded information at the time of diagnosis, Avoiders of Knowledge, who chose to remain uninformed at that time and Weavers to and from Knowledge. The latter chose to fluctuate from information seeking to rejection of education (Pinder, 1990, p.80). It would appear from the interviews with my participants that, with hindsight, they were unanimously Seekers of Knowledge.

McGonigle (1992) studied the well partners of people with a range of chronic illnesses in America. Her findings support the data analysis in my study by stating that an awareness of what to expect in the future can be valuable in avoiding errors in decision making however the author goes on to emphasise that each individual has a different readiness for knowledge and that this variance must be respected (McGonigle, 1999, p. 24).

The relationships between treating medical consultants and patients and their partners have changed dramatically in recent years and this shift in dynamics has resulted in the consultants not being autonomous but instead forming a partnership with patients and family in order to manage the future care of the patient. The distribution of information to partners by the treating medical officer is discussed by Kuyper and Wester (1998, p.245), citing Corbin and Strauss (1988). The authors acknowledged that is vital for partners to have the same information at their disposal as patients. Kuyper and Wester (1998) describe the value of information made available by the General Practitioner to partners of patients with a variety of chronic conditions. Interviews were conducted with a total of 28 participants which identified that 50% reported exhaustion, depression or strain due to relational problems (Kuyper & Weston, 1998, p. 250). The value of available information was supported by a statement from a partner of a patient with a chronic illness: "The most important help he gave me is that he clearly explained to me what exactly the matter was... and that he sensed what I did not dare to ask and what he in fact prepared me for" (p. 250) .

The desire by the participants in my study to be educated or have some knowledge of the beast, or Parkinson's disease, is supported by the literature. In addition the identification of the need for partners of people with Parkinson's disease to "know the beast" validates the 'raison d'être' for self help groups world wide. All but one of the participants in my study had attended a self help group at one stage of their continuum with Parkinson's disease.

The Road Ahead

The honesty of the participants in looking to the future led to the identification of their need to establish and prepare for “the road ahead”. The requirement to project ahead and prepare for the unknown future was identified by the partners interviewed as essential and preparing for the future is the definition given to this sub theme.

For the participant whose husband had died shortly before the interview she was already facing the future she had prepared for during his illness. The impact of Parkinson’s on her husband’s ability to communicate paved the way for the isolation she would experience following his death.

I didn't find being alone such a big problem because in a way having been without proper communication I had already been so alone at night, in the evenings for such a long time that the loneliness doesn't affect me as much as it would people who have a sudden loss of a partner(Colleen).

This participant’s openness during the interview by discussing her relief at his passing clarified the description of her calm response at the time of his death. The realisation that her final loss had been a gradual bereavement assisted in the facing the road ahead She provided advice for others in a similar position.

His passing was in a way a relief. A release. I was well prepared for it because I had been preparing beforehand. That is something I would sort of suggest to everybody who has a person with a chronic illness. When they know it is coming to the end you need to be prepared (Colleen).

However Colleen went on to describe her present grieving as occurring at unexpected situations and again wished to use her experience in order to assist others at their time of grief. This confirmed the recognised need for preparation for “the road ahead”.

However in the last few weeks things have really changed. When I have been going through drawers and things and I find things in cupboards. I have really started getting very upset and emotional which is surprising to me. But I think that is natural. That I didn't do a lot of crying straight after [spouse] passed away and it is coming now and that is probably quite natural. But it is sort of surprising me when it happens because it happens at the most odd times. So that is probably helpful to people who are going to go through the same, that they can expect that and that it is probably quite normal. (Colleen)

The ability to reflect was of benefit to this participant and added weight to the observations and experiences of the other partners interviewed. Her sharing was confirmed by the observation of another participant who admitted. *I'm mentally preparing myself. When you see other friends in similar situations lose their partners you can't help but think how you will be after this (Amy).*

For those yet to face the ultimate loss of their partners it was evident from the interview data that the future or “road ahead” was a major consideration. All the participants acknowledged that they had considered their future although the extent of the confrontation ranged from an awareness of the unknown to the certainty of the final loss. For one participant the absolute honesty that accompanied this revelation must be acknowledged. The ability to project to a life which will not centre on caring, Parkinson's disease and communication changes required both great strength and reflection.

In some ways I am looking forward to it. I am looking forward to being able to be myself again and maybe keep living. That sounds selfish, I know. But I suppose you've got to have something to look forward to. And I look forward to the day when I am not a carer. Not that I am looking forward to [spouse's] death or anything like that because we are so close that of course it will affect me (Amy).

Yet another participant recognised the daily living with loss as both part of the present and preparation for the road ahead. The nature of a chronic condition such as Parkinson's disease was again acknowledged as a factor in preparation for the future. The chronicity of the condition was seen as benefit for participants.

I suppose, in a way, you are lucky in that you are prepared a little bit more for the person to die than someone who doesn't live with someone who has got a chronic illness. Every day you are preparing for that loss. It is an ongoing loss (Eve).

Mc Gonigle (1999) in an American study of forty well wives describes the “ambiguous losses” endured when a husband had a progressive condition. These healthy spouses of men with progressive conditions volunteered to be part of a qualitative study into their situations. The loss experienced by one spouse was so real that she experienced a shock to see him alive at times (McGonigle, 1999, p20). This experience reinforces the expression by the participants in my study of projecting forward to the time of the death of their partners.

The ultimate loss is anticipated not just by the partner but was recognised as impacting on the family as a unit. The insight gained by a participant in observing this impact is reflected in her concern for her children and her added burden in helping them cope with the future they too will have to face. These reflections on the grieving process experienced led to a natural closure to her interview.

The family realise we are losing him. They experience it too. In some ways it is harder for them because they go away and come back to it. When you are living with it all the time it is easier. So you deal with their loss as well. Their grief and everyone else's (Amy).

The progressive nature of Parkinson's disease and the ultimate loss associated with the condition is described as a *visible death* (Debbie), this death affecting the family unit in various ways. For the partner it is a personal loss. *I seem to be losing him fast* (Debbie). The impact on the family is explored in greater detail as it is seen that the personality that was so well known to the participant will not be the personality that will be remembered by the grandchildren.

It is the grandchildren that it is going to impact on. They won't remember [spouse] when he was more alert and more alive. Because he is dying. They won't know the grandpa they would have had if he had't had Parkinson's (Debbie).

While Debbie expressed her grief at the impact of Parkinson's disease on her grandchildren as denying them the right to know the person her spouse was pre-disease, this is not the experience of eight patients suffering from Parkinson's disease interviewed for a study on women's experiences of Parkinson's disease (Caap- Ahlgren, Lannerheim & Dehlin, 2002, p. 92). The participants in this study described feelings of comfort and enjoyment of life in the company of their grandchildren. They identified that the children were accepting of the disease and had not acquired adults' attitudes against people with disability. This conflict in perception between the partner of a person with the condition and the experience of the person with the condition warrants further exploration.

While not openly verbalising the final loss another participant described their thoughts and expectations for the future. Again these expectations focused on the impact on the children. *I think that I will be all right. I think I will cope. But it would be nice to have the family prepared and educated* (Beth).

In addition to facing the inevitable future discussed above the participants recognised that the day to day life with a partner who demonstrates communication changes will impact on them at a more personal level. *Well, I think we have hit rock bottom as far as the fact that [spouse] can't talk. I don't think we can go much further down in the communication stakes. Certainly the body language will get worse. I suppose my frustration will get worse* (Amy). Another participant foresaw changes in her ability to cope and is aware of this as a potential negative aspect of her situation. *I think I will get bitter and twisted. I found for myself that I have to watch for that.* (Beth) The uncertainty of the future is succinctly summarised by the final participant who stated simply. *Time will tell* (Eve).

Conclusion

The necessity to plan ahead, or at least project to the future, was verbalised by the participants as a component of Ways of Coping. This need to prepare for “the road ahead” was common to all the participants regardless of their current situation. The honest acknowledgement by the participants in my study that they all projected their thoughts and plans to the future must be acknowledged by health care professionals involved in the care of people with Parkinson's disease and their partners. Equipping the partners of people with Parkinson's disease for the inevitable future must be a priority for those professionals closely involved in the care of people with Parkinson's disease.

CHAPTER SEVEN

Recommendations for Future Practice and Research

Introduction

This final chapter presents a conclusion to the study on the lived experience of partners of people with Parkinson's disease who demonstrate communication changes. The paucity of literature and research on this topic highlights the void in knowledge and subsequent understanding of the needs of the people facing this challenge on a daily basis. This study has illuminated the often unexplored experiences of those partners and has discussed the findings in relation to literature.

A thematic analysis of the data derived from the interviews with five volunteers resulted in three main themes each with three sub themes. The major themes are defined as: the Partner-Carer Interface, Emotional Turmoil and Ways of Coping. While these themes are a result of the unique personal experiences of the participants in this study they highlight some implications for further research and practice by health professionals in general.

In addition to the major themes, the study resulted in the identification of unaddressed needs of the partners of people with Parkinson's disease which were revealed in the sub themes resulting from analysis of the data. The sub themes addressed the feelings and role status of the partners at the 'time of diagnosis'. The strength or weakness of communication skills prior to the onset of the disease was revealed as an indicator of the impact of the communication changes. The 'sharing of the disease' was identified as a phenomenon which the partners felt was not appreciated by the medical profession and other health professionals. The necessity for available, accurate information or 'knowing the beast' was highlighted as an area for possible improvement. The participants also described their need to 'share the burden' and address the issues of 'social isolation'. The recommendations arising from the study are outlined in relation to the provision of services by both health professionals and self help groups such as Parkinson's Associations.

The findings arising from the study and the subsequent implications for practice are discussed in relation to future nursing research and clinical practice.

My involvement as a researcher in this study has enhanced my knowledge and experience and therefore has contributed to the growth of my role as a Parkinson's disease Nurse Specialist. This study has highlighted areas where the expertise of the Nurse Specialist could be expanded and refined. This was due in part to the development of the critical mode of thinking associated with the research process in general and more particularly by exposure to the intimate experiences of the participants. The areas of future possible expansion of the role will be outlined in relation to clinical practice. In addition, the ongoing provision of care delivered by specialist nurses necessitates the further development of the role resulting in both professional and legal recognition. This chapter will address the recommendations for clinical practice within the existing role and the ongoing development of a Nurse Practitioner role specific to Parkinson's disease

Recommendations for Further Research

The recommendations for further research are discussed from the perspective of the limitations arising both from the profile of the participants and the resulting findings derived from the in-depth interviews. The profile of the participants who volunteered for the study has been discussed in a previous chapter. The recommendations for further research are in part around the specific issues related to the gender and professional background of the partners interviewed. The gender of the participants was not the sole gender related issue discussed by the participants. Therefore as a result of the reported variances in communication skills the recommendations will address further study into gender issues and communication. As this study was confined to Parkinson's disease it will be suggested that transference to other neurological conditions would be of benefit. Each of these recommendations for further research will be addressed individually.

In addition to these recommendations, it must be remembered that this study has explored the personal experiences of five partners of people who demonstrate communication changes resulting from Parkinson's disease. The findings of this study are confined to the experience of these participants and do not result in generalisations. The duplication of this study with larger numbers and varying experiences may result in a diversity of findings which would expand the delivery of care.

Gender of the Participants:

The study explored the experiences of five people living and communicating with their partners who demonstrated the commonly manifest communication changes related to Parkinson's disease. The participants who responded to the advertisement were all female. This demographic detail was not intentionally sought but may have been due to several factors. Parkinson's disease is slightly more common to males than females with a ratio of 3:2 (Waters, 1999, p. 17) therefore it may be assumed that the majority of partners living with people with Parkinson's disease would be female. In addition, the provision of unpaid care predominately falls to the females in the family unit. An Australian study (Dunn & Hammond, 1999, p.29) revealed that 60% of the carers reviewed were female (n= 69). Therefore the gender of the participants in my study is not unexpected.

The availability of evidence based information specific to gender and specifically to male partners of female Parkinson's patients is presently lacking, thus future research in this area would be beneficial to the population of people with Parkinson's disease and their partners. Therefore the exploration of the impact of communication changes should be examined from the perspective of male partners of female Parkinson's sufferers in order to augment the body of knowledge on Parkinson's disease and communication changes.

Gender Difference in Communication:

Two of the participants observed that in their opinion there is a variance in communication skills and strengths according to gender. For one participant the comparison between males and females affected by Parkinson's disease was due to personal comparison of her late mother who had Parkinson's and her husband also diagnosed with this neurological condition. For the other participant the observation that male communication skills were different from those of females was a comment based on her general experience. This phenomenon, as noted in the literature, confirms the need for further study into the possible differences in communication demonstrated by both genders in Parkinson's disease. The availability of information on the possible variances of communication changes between genders would assist with the planning and provision of therapy specific to the individual patient. In turn this would assist the partners of the persons affected. The provision of counselling services based on research derived information would maximise the delivery of holistic care for both patient and partner.

Health Care Background of the Participants:

Three of the five participants in the study were nurses. One was employed as a nurse at the time of the interview and the remaining two had nursing qualifications and experience prior to retirement. The commonality of nurses responding to the advertisement for participants may have been due to a self perceived association with the researcher as a nurse and a desire to further nursing research in a topic of which they had personal experience not only from personal experience, but also from their background of nursing knowledge.

The experiences and explanations of these partners who were previously nurses may have influenced the emergence of the first major theme the Partner-Carer Interface. This may have been due to their familiarity with the label of 'carer' as commonly used by those from their professional background. Their background in professional caring augments the theory of cognitive dissonance. Festinger and Carlsmith (1957) explored the theory that the greater the conflict or dissonance experienced in a situation the greater the belief in the strategy utilised to deal with the cognitive dissonance. For the participants in my study it is possible that the conflict between their nursing role and the emotional role of partner may have magnified the cognitive dissonance experienced because of their professional background. Thus the cognitive dissonance theory supports the verbalised self identification as a carer. A phenomenological exploration of experiences of partners without a health care background may result in contrasting role identification and further understanding of the experiences of partners of people with Parkinson's disease.

Disease Specificity:

Parkinson's disease, with an incidence of 1:1000 for people over 65 and 1:100 over 75 years (Doherty & Lyle, 2003, p. 4) is the most common of the progressive neurological conditions which has the potential to affect communication skills. However it is not the only neurological condition which results in communication changes. Other degenerative conditions such as Motor Neuron disease, Progressive Supra-nuclear Palsy, Multi-system Atrophy and Multiple Sclerosis may result in impaired communication. The exploration of the experiences of partners of people affected by these conditions will add to the body of knowledge regarding these neurological conditions and communication changes. The cumulative effect of such studies will augment the validity of the experiences of those living with uncommon conditions of which there is limited research. In addition, such studies

have the potential to illuminate subtle variances specific to the disease process under examination. It is only by exposing the nuances experienced by those dealing with the disease process on a daily and personal level that health professionals can deliver sensitive care.

Implications for Clinical Practice and Delivery of Holistic Care

This study has revealed a level of knowledge that is based on the honest sharing of intimate thoughts and experiences by the participants. This sharing has resulted in a deeper level of care delivery by the researcher in my role as Parkinson's Nurse Specialist. It is appropriate that this level of knowledge is available to a Nurse Specialist whose position demands the ability to demonstrate critical reflectivity (Conway, 1998, p. 80). Further studies at a similar level will ensure the delivery of holistic care which is evidence based.

Intimacy:

The impact of Parkinson's disease on intimacy has been explored previously from a clinical view point related to impotency and hyperlibidity (Bronner, 2002; Komacher, 2002).

However the innermost responses of the partners in this study regarding the subtle challenges to intimacy wrought by the disease process demand further exploration. The honesty of the participants in my study in describing their response to the emotional and physical changes wrought by Parkinson's disease in their partners has resulted in a deeper level of knowledge on an intimate level. This honesty resulted in the development of the sub theme 'confronting the physical'. This level of honesty has not previously been apparent in the clinical experience of the researcher. Open discussion of this topic may have been limited because of the sensitivity of the topic and a fear of disloyalty to the person with the condition with whom the partner has shared an intimate and formerly satisfying life. It is imperative that the implications of these emotions be explored and information made available to ameliorate the experience of those yet to be impacted by these changes. The combination of the personal experiences of the participants in this study with clinical information on Parkinson's disease and intimacy could result in the development of an information sheet to be made available by Parkinson's self help groups if and when the need was identified. The knowledge that the emotions experienced are not unique could address the emotional turmoil associated with the development of a conflict

of feelings such as disloyalty when the desire for physical intimacy is compromised by the impact of the disease process.

The Changes in Communication Experienced by the Participants

This study set out to explore the experience of the partner of a person with Parkinson's disease who demonstrates communication changes. A phenomenon identified from the data and also from the literature was that the partners who live with the person affected by the disease report that their own communication skills are at risk of deterioration due to lack of interaction, both verbally and non verbally, from the person with Parkinson's disease. The diminishment of non verbal communication skills, such as body language, may result in the loss of a mirroring in communication at a very basic level which has the potential for an impaired ability to read non verbal messages delivered by others. The manifestation of this phenomenon may present as a withdrawal or inability to interact effectively at a social level with others as the skill of communication is not in constant use. This has the potential to be misunderstood and in turn augment the self reported difficulty in communication on the part of the partner "sharing the diagnosis".

The sharing of their experiences by the participants in this study has illuminated an area which deserves further consideration in relating to partners/carers. An awareness of the potential for loss of subtle communication skills will address many issues when health professionals are involved with unpaid carers who once considered themselves partners.

Emotional Support for Partners

The revelation by the participants in this study that they experienced "social isolation" and a thirst for knowledge to face "the road ahead" emphasises the necessity for groups such as Parkinson's Associations. The findings arising from my study have highlighted the void experienced by the participants in having their needs addressed. All of the participants had been involved, at one stage or another, with a Parkinson's Association. These community based organisations fulfil a need primarily aimed at the person diagnosed with the neurological condition. The emotional and educational requirements of those living with the person with the condition necessitate the further development of both support groups and educational seminars aimed at the partners/carers.

This study has allowed a Parkinson's Nurse Specialist to explore the experiences of the partners of a group of people who would routinely be the main focus of her care. The depth of care delivered by this role has developed as a result of the research process.

Implications for the Role of the Parkinson's Nurse Specialist

The role of the Parkinson's Nurse Specialist in Western Australia was introduced in 1998 based on the United Kingdom model. The trial of the one year funding in 1998 has been expanded to incorporate two nurses who primarily service the Perth metropolitan area. The depth of care provided by this service has been the topic of presentations both nationally and internationally (Doherty, 2003; Graham, 2001). The role encompasses the skills necessary to act as a specialist in the field of Parkinson's disease and is currently defined as a specialist role rather than that of a Nurse Practitioner. The level of expertise required to function at specialist level is explored by Fairweather and Gardner (2000). Their qualitative study outlined the necessity for "advanced problem solving skills, innovative and predictive practice which is not environmentally dependent" (p. 29) as being, in part, evidence of the skills essential for specialist practice.

The need for a specialist nursing role in the treatment and management of Parkinson's disease patients is confirmed by the predicted rise in the ageing population which will in turn lead to an increased incidence of this neurological condition. The average age of patients in a community based hospital in Perth in 2003 is 74 years (Dr. B.I. Vieira, personal communication, September 13, 2003). The impact of an ageing population and subsequent increase in degenerative diseases will be that nurses will be required to have more specialized knowledge and resources. The exposure to the needs of people with Parkinson's disease and their partners and families is a daily challenge for all nurses caring for people with Parkinson's disease. The availability of Parkinson's Nurse Specialists who can educate and equip nurses to deliver informed evidence based practice will address the needs of those affected by the condition and their families.

The depth of care delivered by Parkinson's Nurse Specialists in the community is derived from experience and research in the area. The level of knowledge resulting from such exposure is in part responsible for the transition from a novice to expert nurse or practitioner (Benner, 1984). The acknowledgement of this role as a Nurse Practitioner would consolidate the level of care currently available to the person with Parkinson's disease and their family.

The innovative Nurse Practitioner legislation recently proclaimed in Western Australia allows for the designation of the Nurse Practitioner role in a variety of settings however the current legislature in Western Australia does not allow this role to be considered for registration as a Nurse Practitioner. It would seem timely to legitimise the extensive functions of a Parkinson Nurse Specialist by so designating the role as that of a Parkinson Nurse Practitioner. The inclusion of the role of Parkinson's Nurse Specialist as eligible for consideration as Nurse Practitioner would acknowledge the significant and complex nature of the activity which the nurse undertakes in the delivery of holistic evidence based care. For example, this would empower the nurse to act legally when advising and adjusting medication regimes. This could address the potential for a situation where the nurse specialist, who already has an expert knowledge of the medications and possible drug interactions, is currently unprotected by legislation should she/he give advice on this complex component in the management of Parkinson's disease.

Concluding Comments

Parkinson's disease is a common, progressive neurological condition which has the potential to affect all aspects of communication. The exploration of the experience of those most intimately affected by the changes in communication has been, in part, initiated by this study. In order to fully address the needs of this previously silent group of partners/carers it is essential that they are further encouraged to share their experiences and add to the body of knowledge on Parkinson's disease and communication. It is my desire that this study will act as a catalyst for further investigation and delivery of care which has been honed and refined from sensitive research.

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Appendices

APPENDIX A

Parkinson's and Communication Study

A nurse researcher from Edith Cowan University in Perth, Western Australia is seeking to contact partners of people with Parkinson's disease who have difficulties with communication (e.g. unclear speech, slurring, low volume and/or masked expression).

The partners of the people with Parkinson's disease will be requested to share their experience of living with someone with communication difficulties.

Interested partners of people with Parkinson's disease who demonstrate communication difficulties are asked to make contact as soon as possible with the Parkinson's Association in Perth for further information.

**Parkinson's Association of
WA
320 Rokeby Road Subiaco
WA 6008**

Ph. (08) 93816166

APPENDIX B
CONSENT FORM

Have you ever wondered about other people’s experiences of living with a partner with Parkinson’s disease whose communication skills have been affected?

Do you feel that your experiences are similar or different from other peoples?

Would you like to share your experiences and be involved in a study into the experiences of a person living with a person with Parkinson's disease who is experiencing communication difficulties?

The aim of this study is to gain insight into how having a partner with Parkinson's disease with communication difficulties affects your life. Ideally this increased knowledge will provide strategies to support the partners and patients with Parkinson's disease.



By signing this form I am consenting to becoming a participant in this research study which is exploring the lived experience of a partner of a person with Parkinson's disease who is experiencing communication difficulties. He research study is to be submitted to Edith Cowan University as a component of a Masters degree.

I agree to participate in this study, I am a partner of a person with Parkinson's disease who has communication difficulties. I live in the metropolitan area and use English as my first language.

I agree that whilst being interviewed the conversation will be audio-taped, and that the duration of the interview may be between one to two hours. This will take place in a mutually acceptable venue without the company of my partner and the interview will involve being asked to describe my feelings, thoughts, and experiences related to being the partner of a person with Parkinson's disease.

I understand that my participation in this study is completely voluntary. I have the right to withdraw as a participant in this study at any time, and not to answer questions at any stage of the study. I agree that no names or forms of identifying information will be used.

If there are any queries or concerns in relation to participating, please contact Janet Doherty on 9300 5646

Participants signature.....

Researchers signature.....

Date.....

APPENDIX C

Guide for Prompt Questions

1. Can you describe what being the partner of a person with Parkinson's disease who has communication difficulties means to you?
2. How do the difficulties with communication affect you?
3. Can you describe strategies that you use to help you through every day life?

APPENDIX D

I Amy Chadbourne, transcriber of the data, hereby agree to maintain confidentiality regarding the content of the interviews carried out by Janet Doherty with participants in the study on the lived experience of partners with Parkinson's disease who demonstrate communication changes.

Amy Chadbourne
February 2000